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AUSTRALIA

**Exploring the Experiences of and Engagement with  
Australia's Shared Digital Health Record by People Living  
with Complex Chronic Conditions in a Rural Community**

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**A thesis submitted in fulfilment of the requirements for the  
degree of  
Doctor of Philosophy**

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February 2018**

# Abstract

This research explored the experience of people living with complex chronic conditions (CCCs) in a rural community and their engagement with Australia's shared digital health record (SDHR). People living with CCCs in rural communities are considered vulnerable healthcare users and frequently experience unique challenges in obtaining access to quality healthcare. A SDHR may address some of these challenges and facilitate opportunities for quality healthcare provision. However, the evidence suggests that the design and implementation of many SDHRs has been politically motivated, and has relied too much on a perceived user need identified by commercial companies, designers or researchers that has focused on meeting the requirements of healthcare providers or healthcare systems, but has overlooked the needs of the healthcare user.

Australia launched its version of a SDHR, My Health Record (MyHR), in 2012, but enrolment remains low and there are challenges in its practical implementation. There is still little contextual evidence that MyHR supports healthcare users in rural Australian communities with a person-centred or integrated approach to their healthcare provision.

The topic of this research was identified by the community of research partners (hereafter referred to as the research community), i.e., people living with CCCs in rural southern Tasmania, during an annual review of their community healthcare provision. The topic reflects the research community's concern about the capacity of a SDHR to be beneficial for a person living with CCCs in a rural community, and the obstacles that affect their engagement.

To address this community concern required research methods that gathered real-world perspectives of the research community's experiences of and engagement with MyHR. We used subjective qualitative methodology underpinned by a participatory philosophy and a research paradigm that included subjective ontology, extended epistemology, axiology, and community based participatory research (CBPR) methodology.

The research design involved a series of phases to first obtain rich examples of the research community's experience of and engagement with MyHR, and then to rigorously validate these. Each phase progressed through iterations of action and reflection. Following an introductory phase, there were three phases of data collection: pre-experience of MyHR, registration and early engagement with MyHR, and post-experience and engagement with MyHR. Data collection techniques included group meetings, semi-structured interviews and the researcher's reflective journal. The data collection tools included audio recordings, a group guide, a semi-structured interview guide and live interaction with MyHR as a healthcare user. Data were collected over a 12-month period and incorporated concurrent data transcription and verification (member checking).

Data analysis was structured in three phases: data description, data management and data interpretation. The phases were further subdivided into five iterative stages: familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation. This process ensured that the characteristics and experiences of the research community were thoroughly explored and consistently recorded by linking the research objectives to 55 indexed labels that were charted to 13 categories and finally mapped to three themes: self-identity, knowledge, and access. Scrutiny of these themes identified nine findings which, when considered in relation to the research questions, identified the three key findings as the need for **tailored facilitation, resilience** and **reflection**.

Although there is little published evidence that the use of facilitation increases the engagement of vulnerable healthcare users during their introduction to SDHRs, this research identified that **tailored facilitation**—facilitation tailored to recognise the diversity of the healthcare user's needs—could instil and support the competence and confidence required for acceptance of SDHRs.

Although there is also little evidence suggesting a need for building **resilience** in vulnerable healthcare users or their communities during their adoption or use of SDHRs, the results of this research indicate that vulnerable healthcare users should demonstrate and build **resilience** to inform quality healthcare provision and the implementation of SDHRs.

The key finding of **reflection** demonstrates the benefits and challenges of applying a CBPR approach to digital health research. The benefits would not have emerged through a researcher-focused paradigm. The challenges require strong researcher–community partnerships developed through time, trust and flexibility on all sides.

These key findings complement, contrast with, and extend the existing research evidence. The research community was receptive to experiencing and engaging with MyHR and believed that MyHR registration should occur at a national level. However, for MyHR engagement and utility to be realised at a regional and local level, all communities and individuals require contextually appropriate information, training and support.

MyHR does not realise its full potential because system designers and healthcare providers persist in marginalising and undervaluing healthcare users’ real perspectives and requirements. However, the research community’s ability to demonstrate and build resilience suggests that digital health information needs to be relevant and accessible to everyone, irrespective of their physical or cognitive ability and digital knowledge. This research advocates that, rather than these criteria being regarded as a deficiency of the person or community, they should be viewed as a deficiency of the health system and rectified through changes in community healthcare provision.

The research contributed to health informatics and digital health knowledge at three levels: substantive, methodological and theoretical. At a substantive level, people living with CCCs in rural southern Tasmania identified the research topic as reflecting a concern of their community. Their identification of the research topic and their engagement from inception and through all phases of the research enabled the successful design and delivery of a subjective qualitative research project within the field of digital health in a vulnerable community environment.

At a methodological level, this research has contributed by introducing and engaging a rural community in digital health research. The research design challenged and encouraged a traditionally difficult-to-engage vulnerable community to be directly involved in a research community. To extend and complement this focus on shared decision-making, researchers should not rely only on controlled experiments, but should become comfortable with the use of participatory paradigms including CBPR,

a combination of data collection methods, and a thematic framework approach to data analysis. Further, to fully experience and engage in a digital healthcare research requires capacity-building in technology tools and digital healthcare provision. This research significantly contributed by identifying that the principles of CBPR do not consider capacity-building technology and digital healthcare. Therefore, the principles of CBPR need to evolve to recognise that capacity-building in technology and digital healthcare require acknowledgement and inclusion.

At a theoretical level, the research has contributed to digital health research knowledge based on person-centred care. It identified the perception that healthcare provision marginalises and undervalues the capacity of vulnerable healthcare users to benefit from digital health tools. The results highlight that MyHR, and all SDHRs, need to be viewed as operating within the broader context of the provision of preventative and continuing quality healthcare and should be viewed by all stakeholders as an adjunct to any quality healthcare intervention.

In conclusion, enrolment in and engagement with MyHR can enhance the delivery of healthcare, and its implementation should be regarded as a process-improvement strategy driving a change toward person-centred quality healthcare. This research lays the foundations for future studies to address how best to translate the theoretical concept of person-centred care from a complex adaptive system perspective into direct involvement of real people in research using digital health tools. Such studies should ultimately transform the adoption, use and utility of SDHRs, assure continuity of information, and improve outcomes for people living with CCCs in geographically isolated communities.

# Keywords

- Australia's Digital Health Record
- Complex Adaptive Systems
- Complex Chronic Conditions
- Community Based Participatory Research
- Digital Health Record
- Models of Healthcare
- My Health Record
- Person-Centred Care
- Rural Healthcare Provision
- Shared Digital Health Records
- Trust-Centred Relationships
- Vulnerable Healthcare Users

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# List of Abbreviations

- ABS Australian Bureau of Statistics
- ADHA Australian Digital Health Agency
- ADH Australian Department of Health
- AHPRA Australian Health Practitioner Regulation Agency
- AIHW Australian Institute of Health and Welfare
- CDM Chronic Disease Management
- CBPR Community Based Participatory Research
- CCCs Complex Chronic Conditions
- DHHS Department of Health and Human Services
- EHR Electronic Health Record
- EMR Electronic Medical Record
- GP General Practitioner
- HP Health Professional
- ICT Information and Communication Technologies
- IT Information Technology
- LGAs Local the Government Areas
- MyHR My Health Record
- NEHTA National Electronic Health Transition Authority
- NHHRC National Health and Hospitals Reform Commission
- NPS National Prescribing Service
- NRHA National Rural Health Alliance

- OECD            Organisation for Economic Co-operation and Development
- PCEHR        Personally Controlled Electronic Health Record
- PD             Participatory Design
- PHR            Personal Health Record
- POCT          Point of Care Testing
- RAW           Rural Alive and Well
- SDHR          Shared Digital Health Record
- UCD            User-Centred Design
- WHO           World Health Organisation



## **Declaration of Originality**

This thesis contains no material which has been accepted for a degree or diploma by the University or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

Helen Almond, February 2018

## **Statement of Ethical Conduct**

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

Helen Almond, February 2018

## **Authority of Access**

This thesis may be made available for loan and limited copying and communication in accordance with the Copyright Act 1968.

Helen Almond, February 2018

# Acknowledgements

- To my supervisors, without whom this book would not have been started, let alone reached a conclusion, I am deeply grateful. Their vast knowledge, expertise, understanding, encouragement and most of all tenacity have provided me with an education above and beyond this research.
- The research partners were guaranteed confidentiality, so unfortunately I cannot name them individually. Nonetheless, I wish to express my unreserved gratitude to each of them for devoting their confidence, time and effort to the success of this research. In fact, the research would not have been undertaken without their suggestions, spirit, inspiration and generosity.
- Special gratitude is extended to all members of Rural Primary Health Services, Tasmania for their support, guidance and friendship.
- To all of my family, thank you for accepting and tolerating my absence.
- Friends, I thank you for allowing me to be who I am.
- My colleagues, thank you for stepping in, standing by me, listening to me and enduring my constant need for reassurance and understanding.
- Ian, you are my rock and my inspiration, your absolute faith and pride in my efforts have been my greatest source of energy and commitment to conclusion.
- Thank you to the anonymous referees from the conferences at which I have presented papers and posters and the journals in which I have published, for their valuable feedback. I also acknowledge the contributions made by my co-authors in these publications (Appendix A).

I dedicate this work to Mum (1930–2015), for her understanding of and belief in me. Mum, ‘I do care’ Hx.

# Chapter 1: Introduction

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Healthcare is an information rich industry and internationally countries are facing major challenges in trying to deliver quality healthcare services. The confluence of these factors makes the need for a comprehensive system, which not only handles multiple layers of data and diverse information but also improves the flow of this information between key stakeholders (consumers, service providers, government agencies and healthcare managers) ultimately to improve health outcomes and quality of care. A shared digital health record (SDHR), implemented and understood as a contemporary digital resource for quality healthcare provision, may provide some solutions and facilitate opportunities for healthcare provision to vulnerable communities. It is for these reasons that in Australia, the government has responded by building My Health Record (MyHR). When used to engage, collaborate, and communicate, MyHR should be considered an unequalled opportunity to explore the gaps and challenges of equitable healthcare provision. However, in rural communities there remains no contextual evidence that it supports person-centred or integrated approaches for healthcare provision to people living with complex chronic conditions (CCCs).

This research explored the experience of and engagement with Australia's SDHR, MyHR, for people living with CCCs in a rural<sup>1</sup> community. People living with CCCs in rural communities are considered vulnerable healthcare users. They frequently experience unique challenges in obtaining equitable access to all types of healthcare.

This chapter provides the background to the thesis, introduces the research topic, offers a summary of previous research contributions and concludes with a brief review of the remaining chapters in the thesis. The chapter is organised into the following sections:

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<sup>1</sup> The research partners were recruited from two Tasmanian local government areas (LGAs), Central Highlands and Southern Midlands. These LGAs hold Outer regional/Remote Australia classifications of RA 2/3. For the purpose of this thesis the community will be referred to as rural.

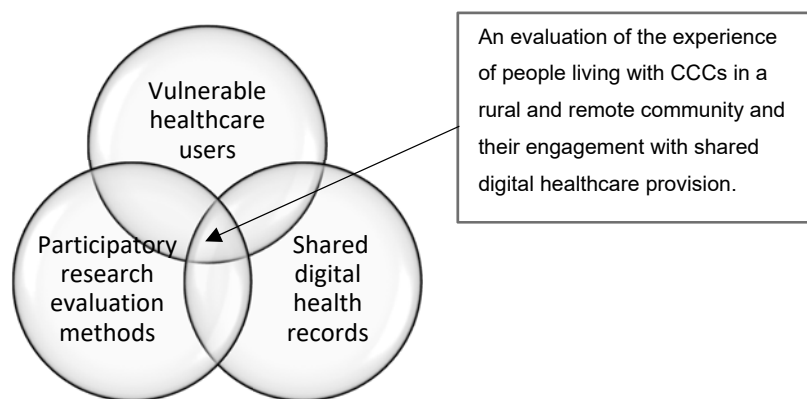
- 1.1 outlines the background to the exploration, and introduces the research domain, the characteristics of people living with CCCs in rural communities, Australia's shared digital health record, MyHR, and the participatory evaluation methods used;
- 1.2 describes the research topic, introduces the aims, objectives, and questions of the investigation, and finally outlines the research approach used;
- 1.3 provides a summary of the research contribution;
- 1.4 provides an outline of the remaining chapters in this thesis;
- 1.5 provides a summary of Chapter 1 and introduces Chapter 2.

## 1.1 BACKGROUND

This section introduces the research domain. It describes the research population of vulnerable healthcare users, people living with CCCs in rural communities, Australia's shared digital health record MyHR, and the community based participatory research (CBPR) methodology used in the research.

### 1.1.1 Research domain

Basic research on how healthcare users engage with SDHRs is needed to provide a foundation for the development of patient-centred consumer health information technology (IT) solutions (Valdez & Flatley Brennan 2015). Exploration of the gap between those directly affected by and knowledgeable about the provision of rural community healthcare and their experience of and engagement with MyHR ideally requires real-world, longitudinal insight garnered from the population themselves. This research is underpinned by contextual and conceptual concerns at the intersection of three research domains: vulnerable healthcare users, SDHRs, and participatory research evaluation methods. These are depicted in Figure 1.



**Figure 1. Location of research arising at the intersection of the three domains**

A goal of healthcare provision should be that every person, family, and community maintains responsibility for their own wellbeing, are informed regarding their health status, and are educated as to possible courses of treatment. It has been argued that SDHRs can assist in meeting this goal by improving information sharing and integration and the quality of healthcare,<sup>2</sup> thereby reducing the burden on healthcare

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<sup>2</sup> In the context of this thesis, quality healthcare provision is described using the six aims for health care: safety, effectiveness, patient-centeredness, timeliness, efficiency and equity (Mitnick, Leffler & Hood 2010).

provision (NEHTA 2012c; eHealth Initiative 2012; Murray, E et al. 2005). To achieve this ideal requires evaluation methods that look beyond experimental or randomised controlled trials toward gathering real-world perspectives of community experiences and engagement with a SDHR. Currently there is a gap in the contextual evidence concerning healthcare provision for vulnerable populations and their experience of and engagement with SDHRs.

The personal and economic burden of CCCs is steadily increasing worldwide (Martin & Sturmberg 2009; McDonald, J et al. 2004). Despite a wealth of evidence demonstrating avoidable risk factors, CCCs are now among the most common and expensive illnesses in Australia (AIHW 2014). The focus of research has shifted from identification of such risk factors to focusing on supporting communities. This requires research and the delivery of healthcare that promotes the participation of those who live with these diseases by making more use of contextually significant evidence and taking a more holistic view (Eysenbach & Jadad 2001; Greenhalgh et al. 2015; WHO 2016b). Addressing the need for delivery of quality healthcare necessitates the use of contemporary research methods that support the revision of existing models of healthcare provision (Battersby et al. 2003; Bodenheimer et al. 2002; Jordan et al. 2008). Vulnerable healthcare users, such as people living with CCCs in rural communities, should be able to provide information about their experience of and engagement with SDHRs that can inform the future requirements for the role of a SDHR in quality healthcare provision. Gathering this knowledge requires that people living with CCCs in a rural community engage with their SDHR. This requires understanding and taking a contextual approach toward the complex transitional<sup>3</sup> requirements of living with CCCs (Greenhalgh et al. 2015; Martin et al. 2011).

Many SDHRs have been designed and implemented from political motives, and rely too much on a perceived end-user need identified by commercial companies, designers, or researchers rather than involving the intended end users, i.e., those

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<sup>3</sup> In the context of this thesis, I have chosen to use the phrase transitional as an umbrella term; this includes the terms: multifocal (occurring in more than one focus or location), and non-linear (a system where many components are interacting and inter-dependent under, a continual state of change). However, for the sake of reference accuracy, I have retained the original choice of term in all quotations and references to publications.

receiving or involved in providing healthcare (Greenhalgh et al. 2010b; Jolly 2011; van't Riet et al. 2001). This means that the perceived user need of SDHRs and their resulting design has focused on meeting the requirements of healthcare providers and the healthcare system. This has had the consequence of overlooking the needs of the healthcare user (Bardach & Cabana 2009; Beasley, Holden & Sullivan 2011; Bonner et al. 2010; Campbell, E et al. 2009; Campbell, E et al. 2006; Cresswell, Worth & Sheikh 2012; Greenhalgh et al. 2010b; Harman et al. 2012; Holden 2010). Improving the uptake and influence of SDHRs for vulnerable healthcare users requires evaluation methods that go beyond the use of experimental studies and randomised controlled trials (Sturmberg 2014; van Gemert-Pijnen et al. 2011), which are not designed to evaluate contemporary SDHRs from a contextual perspective of complex transitional situations.

Evaluating the end users' experience of and engagement with digital technology, including SDHRs, requires the systematic capture of nuanced evidence from a particular person and community and its perception as complementary rather than inferior to epidemiological evidence (Cummings, Chau & Turner 2009; Greenhalgh et al. 2015). This type of evidence requires qualitative exploratory studies that gather subjective information and allow deeper understanding than epidemiological studies (Greenhalgh et al. 2015; van Gemert-Pijnen et al. 2011). People living with CCCs in rural communities are not units or factors of production; they have an identity and live in families and in local and broader communities. The integration of SDHRs into their healthcare provision, to maintain a record of their CCCs and combined healthcare information about their conditions, should be considered an opportunity to explore the gaps and challenges in accessing healthcare for people living with CCCs (Eysenbach 2000).

Hills and Mullett (2000) suggested that good evidence-based practice is more than having choices; thirteen years later McDonald, K (2013) continued to argue that it should be based on representation and consideration of all stakeholders, especially those receiving healthcare, and include their experience of and engagement with any SDHR, while Greenhalgh et al. (2015) recommended that evidence-based practice must be based on participatory knowledge co-created by the community. The subjective, qualitative CBPR methodology, underpinned by a participatory paradigm,

focuses on practical issues and recognises the value of the contribution of community members to the co-creation of new knowledge (Hills & Mullett 2000; Somekh 2002).

Currently, people living with CCCs residing in rural Australian communities have limited access to healthcare, which is delivered according to a narrow, paternalistic, epidemiological research-based practice (Martin & Sturmberg 2009). For these vulnerable healthcare users, there remains no contextual evidence that SDHRs support their access to quality healthcare. It is therefore appropriate that the research involve people living with CCCs in a rural community, and explored their experience of and engagement with Australia's SDHR, using CBPR.

### **1.1.2 Vulnerable healthcare users**

People living with CCCs are considered vulnerable healthcare users because

[CCCs] kill 40 million people each year, equivalent to 70% of all deaths globally. 15 million of all deaths attributed to [CCCs] occur between the ages of 30 and 69 years (WHO 2015).

CCCs are described as co-occurring long-term conditions that result from a combination of genetic, physiological, environmental and behavioural factors (Martin & Sturmberg 2009; Murray, E et al. 2005; Sevvick et al. 2007; WHO 2015). People living with CCCs have long-term transitional health and social care requirements. At the very minimum, they need reliable ongoing healthcare information about their conditions, the various available treatment options, and healthy coping behaviours to assist with everyday management of their conditions (Barnett et al. 2012; Bower et al. 2011). Without quality care and involvement in their healthcare provision, these people may seek out healthcare information and self-monitor their conditions via lay networks and online support groups, with or without the knowledge or support of their healthcare provider (Lupton 2013).

The overall burden of CCCs is steadily increasing, and CCCs are now among the most common and expensive illnesses worldwide (Kamerow 2012; NPS 2013). Rural populations are identified as vulnerable healthcare users because they disproportionately bear the burden of CCCs. This burden is increased by the inability of such communities to access appropriate quality community and specialist healthcare, which in turn perpetuates a continuing decline in their experiences of CCCs (Sturmberg 2014).



In Australia, about half the population has one chronic disease and around 20% has at least two (ABS 2016b). The prevalence of CCCs can be attributed to increasing risk factors, an ageing population, the improved detection and diagnosis of diseases, and the widespread persistence of poor lifestyle choices (poor diet leading to obesity and other conditions, sedentary behaviour, the use of tobacco, and the overuse of alcohol) (AIHW 2013c). Many chronic conditions are preventable or manageable in people who have access to quality healthcare provision that addresses the physical and psychological requirements of healthy coping behaviours (including controlling body weight, eating nutritious foods, increasing physical activity, reducing alcohol intake, and avoiding tobacco use) (AIHW 2013a; Katon et al. 2005).

As has been demonstrated internationally, the health outcomes of rural Australian populations are equally affected by their environment because they have inadequate access to primary and specialty healthcare, education and income (AIHW 2016; eHealth Initiative 2012). Similar to the rest of Australia, rural areas in Tasmania have reported an increased prevalence of risk factors and worse health outcomes compared with urban or semi-urban areas in Tasmania (DHHS 2013). This means that these individuals and communities are not successfully managing their CCCs. Inadequate access to primary and specialty healthcare and health education is leading to lower health literacy and therefore a less accurate understanding of CCCs and their associated risks. People living with CCCs in rural communities are also less likely to discuss psychosocial issues with their healthcare providers, community, or family, further increasing the risk of comorbid depression (Wan, Vo & Barnes 2012). Education about and involvement in the prevention, treatment, and management of CCCs is a fundamental component of quality healthcare for these individuals (Homko et al. 2008).

Supporting people living with CCCs in rural communities during their experience of and engagement with a SDHR may provide an opportunity to better meet the needs of these vulnerable healthcare users and assist them in identifying and achieving improved health outcomes, while also providing contextual knowledge about what is required to facilitate their experience of and engagement with MyHR.

### 1.1.3 Shared digital health records

During the 1960s an American physician, Dr Larry Weed introduced the first electronic health record, recognising that medical care was becoming more complex and the importance of integrating detailed patient data with comprehensive medical knowledge. From this time, the use of a problem orientated medical record became a routine clinical phenomenon (Weed 1964, 1969).

In 1998, all member countries of the European Union Data Directive were required to enact legislation to allow healthcare users access to their medical records (Eysenbach & Jadad 2001). Continuing requirements to improve personal health and reduce the burden on healthcare provision, together with advances in digital healthcare, encouraged the integration of new types of information and led to the development of SDHRs (Kopetsky 2011). When used appropriately, SDHRs can provide continuity of information, track quality, facilitate healthcare user empowerment, and reach isolated rural communities (WHO 2016b).

In 2012, Australia launched its version of a SDHR, the Personally Controlled Electronic Health Record (PCEHR). Its intention was to securely record demographic information and standardised information about healthcare events such as hospital admissions, discharge summaries, referral letters, and pathology results, that were uploaded by healthcare providers or other authorised users. Information from sources such as the Medical Benefits Schedule and Prescribing Benefits Schedule were also to be included. The developers of the PCEHR also anticipated that the healthcare user would add information to the record, and designed the system to allow the healthcare user to choose which information they included in their PCEHR and shared with specified healthcare providers. The vision for the PCEHR was that it would empower and encourage healthcare users to take responsibility for their own wellbeing, be informed regarding their health status, and educated as to possible treatments. The PCEHR would provide a mechanism for ongoing communication between approved healthcare providers and the healthcare user for the management of their healthcare (NEHTA 2012a).

From the outset, the roll out of the PCEHR encountered problems. By 2013 only three and a half per cent of the total population had registered, and the estimated cost had escalated to \$1.5 billion (NEHTA 2013). To address the poor uptake and the

difficulties in implementation, including but not limited to end-user expectations and involvement, the Federal Minister for Health announced a review of the PCEHR (NEHTA 2013b). A panel of professional and political personnel made 38 recommendations that were summarised as five elements intended to:

- support more rapid realisation of the benefits;
- focus on improving the value for users;
- improve incentives for a significant number of stakeholders in the private sector to invest in and embrace the system;
- improve governance to better align the needs of the target users with the delivery of function;
- minimize ongoing costs of development and maintenance of the system while recognizing the need for ongoing investment (NEHTA 2013b).

In late 2015, the PCEHR was renamed My Health Record (MyHR). The review panel recommended the name change to reflect a partnership between the healthcare provider and the healthcare user, while retaining all of the personal controls that existed in the PCEHR (NEHTA 2013b).

The national program of MyHR implementation continues to struggle. Problems include:

- a lack of contextual evidence of healthcare user engagement with MyHR or that it supports equitable integrated healthcare provision;
- costs continuing to spiral to more than \$2 billion, \$400 million a year (Reichert 2017);
- that only 5.4 million users are registered (ADH 2018).

A SDHR should be regarded by healthcare users and healthcare providers alike as fundamental to care: a person-centred shared digital health system within a complex healthcare environment (Project Integrate 2016). MyHR is available to different sets of stakeholders including healthcare service providers, managers, government bodies and, most importantly, healthcare users.

MyHR can provide a secure digital summary of a person's health by integrating some healthcare user data with comprehensive medical knowledge. People requiring healthcare can add to their SDHR, and can control who is allowed access and what they upload. MyHR, if implemented and integrated effectively, allows healthcare users and their agreed registered healthcare providers to view and share digital health information<sup>4</sup> (Muhammad, Teoh & Wickramasinghe 2012). MyHR offers the opportunity for quality healthcare provision for disease prevention, management, treatment, and a reduction in disparities in healthcare access (eHealth Initiative 2012; Murray, E et al. 2005).

The Australian Digital Health Agency (ADHA)<sup>5</sup>, formerly the National E-Health Transition Authority (NEHTA), indicated early in its delivery of MyHR that it was expected to improve delivery of chronic disease management services (NEHTA 2012b). However, there remains little evidence of this, and the facilitation of MyHR implementation is inadequate (Spriggs 2013). This raises concerns regarding the continued failure to address the widening disparities in the quality and value of healthcare provision to vulnerable people, families, or communities who live in unusual and unpredictable circumstances (Greenhalgh et al. 2015; Showell & Turner 2013), including those people living with CCCs in rural Australian communities.

#### **1.1.4 Participatory research evaluation methods**

Internationally the focus of contemporary healthcare research has shifted to methods that embrace the participation of those who live with the disease, take a more holistic view, and make more use of contextual evidence that supports communities (Eysenbach & Jadad 2001; Greenhalgh et al. 2015; WHO 2016b). Gathering evidence concerning the experiences of people living with CCCs in rural communities and their engagement with the provision of shared digital healthcare requires a contextual approach to understand the complex requirements of their CCCs and their experience of and engagement with their SDHR. It is vital to use subjective qualitative assessment methods, rather than purely quantitative

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<sup>4</sup> Digital health electronically joins points of care so that health information can be equitably shared to deliver timely quality healthcare

<sup>5</sup> In 2016 further federal funding was made available for Australia's Electronic Health Records to increase eHealth governance arrangements consistent with the Review. This included transfer of activities, resources and the MyHR operating system from the NEHTA and the Department of Health to the ADHA.

information, to allow understanding of the contextual perspectives of community values and needs (Sweeny, Pritchard & Yao 2010). In the past, evidence-based research and practice has based decisions about what constitutes effective or efficient practice on quantitative data (Greenhalgh et al. 2015). Most current models continue to depict chronic conditions as a single, fixed disease entity with stable properties; they often portray the emotions of healthcare users about their condition as constant. In reality, the symptoms of CCCs are transitional and fluctuate significantly from day to day, as does the importance a person places on their illness (Greenhalgh et al. 2015; Martin et al. 2011). Illness is a small part of what it means to live with CCCs: most of the time, it is living that is important, not the CCCs (Greenhalgh et al. 2015). The evidence-based approach tends to depict a long-term condition as periodic ‘illness exacerbations’ that prompt the person living with CCCs to seek care. However, the person may experience their CCCs not as an illness but as a fact of life that must be accommodated (Greenhalgh et al. 2015; Martin et al. 2011).

Digital health information, including SDHRs, has the potential to engage people living with CCCs in the management of their healthcare by providing opportunities to access their health information. This can empower these people to ask questions, communicate concerns, identify and assess alternatives, reflect on progress and, where required, alter their health behaviour (Unertl et al. 2015). However, despite its availability, the number of people living with CCCs in rural communities who access and use MyHR is still low (Almond, Cummings & Turner 2013, 2015, 2016, 2017). Further, the uptake of MyHR among vulnerable healthcare users, including people living with CCCs in rural communities, appears problematic.

Participatory research evaluation methods are an approach that may improve the engagement of vulnerable healthcare users in the research and practice of quality healthcare provision (Wallerstein & Duran 2006). CBPR methodology, which originated in the public health field, is a collaborative approach that involves evolving, equitable research partnerships between academic researchers and community members (Israel, B , Eng & Schulz 2013), and actively involves community members in the research from topic definition to translation of results.

Evidence generated by research should take into consideration who asks the questions, who defines the outcome measures, who interprets the findings, and who

disseminates the outputs (Mockford et al. 2012). Researchers are now being encouraged to embrace the input of healthcare users at each of these steps (Greenhalgh et al. 2015). During an annual review of their rural community healthcare provision, people living with CCCs in rural southern Tasmania identified the research topic as reflecting a concern of their community. They wanted to know in what capacity a SDHR could be beneficial for a person living with CCCs in a rural community and what obstacles they could encounter during their experience of and engagement with the SDHR.

Because the research partners and their community (hereafter referred to as the research community) identified the topic of concern, we considered it appropriate that the research was performed using a participatory philosophy and paradigm that recognised a subjective ontology, an extended epistemology, axiology, and CBPR methodology. This ensured that the research community was actively engaged at all stages from topic definition to translation of results and benefitted from their participation. The rationale for using a participatory paradigm was to provide:

- an equitable, interactive, iterative framework;
- a requirement for and acknowledgement of the involvement and contribution of the research community;
- recognition of how the research affected and effected the research community's background and experiences;
- an exploration and acceptance of the social world of the research community;
- reflexivity from the researcher's own perspective (Mertens 2005; Ritchie & Lewis 2003).

The CBPR methodology provided a real-world, collaborative framework for gathering contextual, subjective, qualitative evidence about the experience and engagement with MyHR of people living with CCCs in a rural community.

## **1.2 RESEARCH TOPIC**

This section describes the research topic, introduces the aims, objectives, and questions of the research and outlines the research approach.

Managing the rising prevalence of CCCs is a major challenge facing governments and healthcare systems internationally. Many people now live with more than one CCC. Eighty per cent of people with CCCs can effectively engage and better manage their conditions if they are involved in their healthcare provision (eHealth Initiative 2012). The progression of CCCs is transitional and requires continuity of care. Changes in health events can, if communicated effectively and treated early enough, respond well to care, either medical intervention or community and carer support (Martin et al. 2011; Martin & Sturmberg 2009).

Receiving quality healthcare, particularly when living at a distance from the nearest provider, is a barrier that may be overcome by using a SDHR. Full engagement of healthcare users with a SDHR allows complete assessment, interpretation and communication of the changing requirements of their complex health conditions, and far more effective management of required interventions. A SDHR can offer efficiencies in the longitudinal provision of quality healthcare. It can facilitate continuity of care across a range of settings (personal, public, primary, community, secondary, tertiary and palliative care) and the transfer of real-time complex clinical and social knowledge in efficient and appropriate ways (Primary Health Care Advisory Group 2016). Thus, vulnerable communities can be supported and involved in the changes needed to meet the transitional requirements of their CCCs.

A successfully integrated SDHR can deliver substantial benefits to people requiring healthcare and to healthcare providers, but for it to be supported and engaged with, it must take into account all their contextual concerns (Jolly 2011). If MyHR is considered an opportunity to meet the requirements of person-centred healthcare provision, it offers the opportunity of engaging and involving people with CCCs in the provision of that quality healthcare. However, there is currently no practical or articulated structure for community implementation of MyHR.

Between 2012 and 2016, MyHR has received personal registrations from only eleven per cent of the total population (ADH 2016b). These registrants are essentially innovators or early adopters. The roll out of MyHR at national, regional and, most importantly, local community levels is costing billions of dollars. At the same time people living with CCCs in rural communities continue to face challenges in obtaining access to quality healthcare. This highlights questions about why and how

MyHR may be able to support those living in rural communities to address their real problems in accessing care. Investment in MyHR, as opposed to direct service delivery raises a point of contention for these vulnerable communities. Currently there remains no evidence that MyHR supports personal engagement or integrated healthcare provision in local communities. Vulnerable healthcare users continue to access healthcare within paternalistic siloed models of care.

A rural southern Tasmania community identified the topic of this research. They wanted to know how a SDHR could be beneficial for a person living with CCCs in a rural community and what obstacles they could encounter during their experience and engagement with the SDHR. To ensure that the research community remained actively engaged throughout and benefitted from their participation in the research, we considered it appropriate that the research was conducted using a participatory philosophy and paradigm and CBPR methodology. This provided a cooperative community framework for gathering subjective, qualitative evidence at personal and contextual levels that were appropriate for evaluating the experience and engagement with MyHR of people living with CCCs in a rural community.

### **1.2.1 Research aim**

The research aimed to emphasise practical outcomes identified by exploring the experience of people living with CCCs in a rural community in their engagement with Australia's shared digital health record, MyHR.

### **1.2.2 Research objectives**

The research objectives within the overarching aim of the research were:

**Ro1.** To clarify what people living with CCCs in a rural community require from MyHR.

**Ro2.** To recognise how people living with CCCs in a rural community experience MyHR.

**Ro3.** To investigate why people living with CCCs in a rural community engage with MyHR.

### **1.2.3 Research questions**

The research questions will address the research objectives:



**Rq1.** What is the experience of MyHR for people living with CCCs in a rural community?

**Rq2.** Why do people living with CCCs in a rural community engage with MyHR?

#### **1.2.4 Research approach**

Gathering contextual evidence of the experience<sup>6</sup> and engagement<sup>7</sup> of a community with MyHR requires the systematic gathering of real-world narratives that cannot appropriately be measured or translated into numbers. Measurement and numerical analysis methods can diminish or overlook the personal and contextual aspects of the information (Greenhalgh et al. 2015; Trickett 2011). In the past, ‘person-centred’ evidence has referred to the gathering and conflating of objective quantitative data upon which to make decisions about healthcare provision. A medico-defined ‘patient’s agenda’ has been imposed on people who live with CCCs (Greenhalgh et al. 2015; Hills & Mullett 2000). To gather subjective, contextual evidence about people living with CCCs in a rural community and the delivery of their community healthcare, and to answer the research questions, required the development of equitable and co-operative relationships between all research partners including the researcher. These relationships could then allow contextual decisions about the creation and delivery of quality healthcare. Therefore, the research adopted a participatory philosophy and paradigm with the characteristics of subjective ontology, an extended epistemology, and axiology, together with the use of CBPR, a subjective qualitative methodology (Heron & Reason 1997). The CBPR methodology was inclusive of the research partners and recognised the affect and effect of their background, experiences and unpredictable social world, while acknowledging the researcher’s own perspectives reflexively (Mertens 2005; Ritchie & Lewis 2003).

The use of CBPR methodology requires a deep belief in partnership (Minkler 2005). This methodology enabled a transparent exploration of a rural community and their personal understanding and meaning as they experience the real world.

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<sup>6</sup> In the context of this research, the concept experience of MyHR is described as, an observation of developing knowledge and practical contact with their MyHR.

<sup>7</sup> In context of this research, the concept of engagement with MyHR is described as, the process of, committing to, becoming involved in and developing an understanding between the partner, the research community and MyHR.

[The] synergy that partners seek to achieve through collaboration is more than a mere exchange of resources. By combining the individual perspectives, resources, and skills of the partners, the group creates something new and valuable together—something that is greater than the sum of its parts (Lasker, Weiss & Miller 2001, p. 184).

The CBPR methodology supported the researcher and provided them with the facility to research with, rather than for, a traditionally difficult-to-access community. The methodology did not involve economies of scale, and addressed community suspicion of research by actively involving the community as partners engaged in the research at all stages from topic definition to translation of results. Thus, as a research community the partners became key informants about their community culture.

This research design required flexibility to respond to the emerging needs of the research community, anticipation of the unpredictable needs of living with CCCs, and what they required of MyHR. Once ethical approval (HREC-H0013781) and local approval were granted, Tasmania Rural Primary Health Services arranged three local rural group meeting venues and invited people from the community (as depicted in section 3.3.2, Figure 5) who were living with two or more CCCs, to attend one of the three introductory group meetings. Nineteen people living with two or more CCCs were recruited as the research community. Data were collected from February 2014 to January 2015 in three phases:

- phase one: pre-experience of MyHR;
- phase two: registration and early engagement with MyHR;
- phase three: post-experience of and engagement with MyHR.

Data collection involved group meetings, individual semi-structured interviews (SSIs) and the researcher's reflective journal. During each data collection phase:

- three group meetings, lasting between 90 and 120 minutes were facilitated by the researcher;
- SSIs with each research partner, lasting between 60 and 90 minutes, were conducted by the researcher;
- the researcher maintained a reflective journal.

Data collection tools included a voice recorder, group and interview guides and the MyHR personal health record (PHR) portal, as described in section 2.5.2, Figure 2.

Data were transcribed concurrently with data collection; this assisted the verification of transcripts by the partners and the groups (member checking). All voice-recorded encounters were transcribed verbatim, ensuring that data not commonly repeated were not missed, that all data from all partners were considered, and that no data were overlooked. Notes and memos for the reflective journal were recorded on the transcriptions.

Data analysis was structured using a transparent systematic thematic framework approach. Its aim was to map themes and identify findings for interpretation and discussion. This was achieved through three iterative phases of data:

- data management: included iterative stages of familiarisation with the transcribed data, identifying a thematic framework, indexing labels and charting the labels to categories;
- data description: included mapping the categories to themes;
- data explanation: included understanding and interpretation of the findings.

Data management was initiated by achieving familiarity with the transcribed data by reading and re-reading each transcript, repeatedly listening to the audiotapes, and recording initial thoughts and recurrent ideas. An initial framework was developed by drawing from *a priori* and emerging research community views. Organisation and review of the data involved indexing the partners' accounts to 55 labels and charting these to 13 categories. Data description was accomplished by mapping the categories to three themes: self-identity, knowledge, and access; this process identified nine findings. Data explanation involved interpretation of these nine findings which, when considered in relation to the research questions, led to the emergence of three key findings. These were described and discussed in a way that addressed the research questions and complemented, contrasted with, and extended the existing evidence.

By facilitating a participatory paradigm, the principles of CBPR, and a thematic framework approach to data analysis, the research clearly demonstrated how involvement of a rural community and their inclusion in digital healthcare research could support better design and delivery of SDHRs. A vulnerable community

participated in the generation of knowledge for future communities, and although the researcher facilitated the research, the research community accomplished it. This endorsed shared responsibility and ownership, and ultimately enhanced our understanding of the experience of and engagement with MyHR for people living with CCCs in a rural community.

### **1.3 SUMMARY OF RESEARCH CONTRIBUTION**

This section provides a summary of contributions the research makes to digital health knowledge at three levels: substantive, methodological and theoretical.

At a substantive level, people living with CCCs in rural southern Tasmania identified the research topic because it reflected a concern of their community. Their identification of the research topic and their engagement from inception through all phases of the research enabled the successful design and delivery of a subjective qualitative research project, within the field of digital health research, in a vulnerable community environment. The research community recognised and valued the availability of MyHR and the perceived opportunities it offers as part of their contemporary healthcare provision. They requested access to a SDHR where they, their carers, and their healthcare providers could communicate and collaborate to address their needs, their CCCs and, principally, their transitional complex care pathways. For a person living with CCCs in a rural community, person-centred care should be delivered as equitable, integrated digital healthcare. MyHR can enhance healthcare user interactions, thereby increasing the chance of access to timely communication between all stakeholders, irrespective of the physical, mental, or cognitive abilities of a person living with CCCs.

At a methodological level, this research contributes by introducing and engaging a traditionally difficult-to-involve rural community in digital health research. The research community's willingness to participate in collaborative digital health research, the use of CBPR methodology, and the thematic framework approach to data analysis allowed their involvement and their development of an in-depth understanding of their experience of and engagement with MyHR. The combination of CBPR and a thematic framework approach to data analysis provided strength to the research design. The method resulted in the collection of rich data in a humanistic and natural manner. The research contributes further by identifying that

the principles of CBPR need to evolve to incorporate capacity-building in digital healthcare technology.

The adoption of a participatory paradigm, the principles of CBPR, realistic data collection methods, and a thematic framework approach to data analysis contributed by demonstrating that the use of this combination of methodologies provided strength to the research design, resulting in the collection of rich data in a holistic manner. It involved, challenged, and encouraged a vulnerable community in the direct organisation of learning between the partners, the groups, and the researcher as a research community. The method encouraged people with CCCs living in a rural community to adopt the concept of MyHR as positive adjunct to their quality healthcare provision.

This research contributes substantially by identifying that the principles of CBPR need to extend to incorporate contemporary healthcare provision, technology, and digital healthcare capacity-building, a combination of data collection methods, and a thematic framework approach to data analysis, thereby really studying personally and contextually significant evidence in a digital healthcare environment.

At a theoretical level, this research has identified that healthcare provision is perceived as marginalising and undervaluing vulnerable healthcare users' capacity to benefit from digital health tools. The research contributes to digital health research knowledge because it focused on person-centred care from a complex adaptive system perspective. The research highlights that SDHRs must be viewed as an information system operating within the broader context of continuing and preventative quality healthcare provision. The research proposes that the individual, the community, healthcare providers, and educational institutions should view SDHRs as an adjunct to any quality healthcare intervention, because all stakeholders require that information be safely provided to the right person in the right place at the right time. Researchers, policy and decision makers at national, regional, local and institutional levels should consider incorporating person-centred care from a complex adaptive system perspective in future quality digital healthcare initiatives. Research designs should involve participatory co-design rather than controlled experiments alone. This would balance the focus on shared decision-making and collect holistic evidence on how to provide quality digital healthcare.

## **1.4 THESIS OUTLINE**

This section provides an overview of the remaining chapters contained in this thesis.

### **1.4.1 Chapter 2 Literature review**

Chapter 2 presents a review of the appropriate existing evidence relevant to the research domains of vulnerable healthcare users, shared digital health records, and participatory research evaluation methods. The chapter also describes and discusses models of healthcare, providing a theoretical background for the discussion.

### **1.4.2 Chapter 3 Research methodology**

Chapter 3 presents, describes and discusses the research methodology used to address the research questions identified in section 1.2.3. It introduces the research philosophy, describes and discusses the participatory research paradigm, and discusses subjective ontology, extended epistemology, and axiology. It then introduces the research strategy, CBPR, and describes the community, the research community, the research partners, and the researcher before outlining the research design for collection and analysis of the data, including the recruitment of the research partners and how research validation and rigour were achieved. It also describes how the research community ensured that the principles of CBPR were addressed, and recognises the ethical considerations required for the delivery of the research.

### **1.4.3 Chapter 4 Analysis**

Chapter 4 presents an in-depth systematic data analysis with respect to identifying evidence and linking the evidence to the research objectives outlined in section 1.2.2, to identify findings. It includes a transparent, systematic example of the thematic framework analysis, tabulated descriptors of each label, category and theme, and examples of the narrative indexed to labels, charted to categories, and finally mapped to themes. It identifies 16 potential findings prior to suggesting nine findings.

### **1.4.4 Chapter 5 Interpretation of findings**

Chapter 5 provides an interpretation of the nine findings identified in Chapter 4 with respect to their substantive relevance, inclusion, and value, communication, confidence, and competence, accessibility, interoperability, partnership, learning environment, and community knowledge. It identifies three key research findings.

#### **1.4.5 Chapter 6 Discussion of key research findings**

Chapter 6 describes and discusses the three key research findings, i.e., the requirements for **tailored facilitation**, **resilience** and **reflection**, which emerged from consideration of the nine findings in relation to the research questions identified in section 1.2.3. It describes and explains how these findings address the research questions and critically discusses each finding alongside the appropriate evidence.

#### **1.4.6 Chapter 7 Conclusion**

Chapter 7 concludes this thesis by seeking to synthesise the topics discussed in Chapter 6. It restates and provides answers to the research questions, extracts key aspects of the relevant literature, and explains how these support or contradict the research findings. It then presents the contributions of the research to digital health knowledge at substantive, methodological, and theoretical levels, outlines the scope and limitations of the research, and makes recommendations regarding directions and areas for future research at policy and implementation, community and personal, and research levels.

### **1.5 SUMMARY**

Chapter 1 has provided background to this research. It has described and discussed the research topic, introduced the research aim, research objectives, research questions and research approach. The research objectives and questions have been presented in the context of exploration of the experience of and engagement with MyHR of people living with CCCs in a rural community. It has described the contribution of the research to digital health knowledge at substantive, methodological, and theoretical levels.

Chapter 2 will present a review of the appropriate existing evidence in the context of the research domain outlined in section 1.1.1.

# Chapter 2: Literature review

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Chapter 2 presents a review of the appropriate existing evidence relevant to the research domain of vulnerable healthcare users, SDHRs, and participatory research evaluation methods. The chapter also describes and discusses models of healthcare, providing a theoretical background for the discussion. The chapter is organised into the following sections:

- 2.1 describes and discusses health and provides context for the research with regard to healthcare provision;
- 2.2 describes and discusses vulnerable healthcare users, people living with CCCs; it is subdivided to provide a description of the characteristics of CCCs and a discussion regarding the burden of chronic disease;
- 2.3 describes and discusses rural health in Australia including healthcare provision, the demonstrable need to provide these populations with appropriate resources, and health in Tasmania;
- 2.4 provides a background to shared digital health records; it is subdivided to offer an historical overview and a description and discussion of digital health record systems and to characterise the elements of digital health and finally the role of a SDHR;
- 2.5 describes and discusses MyHR, in the context of shared digital health provision; it is subdivided to provide a discussion regarding international approaches toward implementation and the position of MyHR in digital health systems;
- 2.6 describes, discusses and compares three participatory research evaluation methods: CBPR, participatory design and user-centred design. The comparison emphasises that CBPR is the only approach that incorporates a partnership from the inception to conclusion of the research and enables the researcher to engage as a trusted member of the community. It also



emphasises that although the community includes the intended users of MyHR, not all partners may be the intended users;

- 2.7 describes and discusses models of healthcare; it is subdivided to provide a discussion regarding the theoretical context and to review complex adaptive systems and person-centred care. Identifying a theoretical context provides a framework that assists the research discussion;
- 2.8 provides a summary of Chapter 2 and introduces Chapter 3.

## 2.1 HEALTHCARE PROVISION

This section describes and discusses health and provides the context for the research with regard to healthcare provision. Since 1948 (last amended 2005), the World Health Organisation (WHO) has described health as

[A] state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO 2006).

Rogers and Veale (2000) refer to the WHO description of health as a complete state of wellness rather than an absence of disease. They suggest that this requires the successful function and development of an integrated community that reflects local needs through the delivery of multiple sustainable and affordable health, social, educational, industrial, and agricultural services and technology.

The descriptions used by both Rogers and Veale (2000) and the WHO (2006) have been challenged by Huber (2011, p. 235), who considers that an ageing population with increasing chronic illnesses is now the demographic norm and that therefore, earlier definitions are redundant and ‘counterproductive’. Huber (2011, p. 236) suggested that rather than using a static definition, health is better described as a dynamic concept based on ‘resilience, integrity, equilibrium and wellness’. He concludes by describing ‘health as the ability to adapt and self-manage’. Huber’s definition appears to be the most appropriate for the purpose of this research. It takes into consideration the effect that an ageing population and an increasing burden of CCCs will have on the delivery of future healthcare and health systems.

Prior to describing and discussing the burden of CCCs within healthcare and health systems, it is necessary for clarity to provide definitions and explanations of each of

these terms as used throughout the thesis. Martin and Sturmberg (2009) cite the WHO (2003, p. 572) definition of healthcare as:

[T]he prevention, treatment and management of illness, and the preservation of mental and physical well-being through the services offered by the medical, nursing and allied health professions.

They continue by describing health systems as the ‘institutions and resources that undertake health actions’ (Martin & Sturmberg 2009, p. 572). The descriptor ‘health systems’ includes new types of information and communication technologies (ICT) that can provide continuity of information, engage and empower the healthcare user, and reach geographically isolated communities (WHO 2016b). Throughout the thesis, ‘healthcare provision’ is defined as the combination of healthcare and health systems.

## **2.2 VULNERABLE HEALTHCARE USERS - COMPLEX CHRONIC CONDITIONS**

This section defines and discusses vulnerable healthcare users and people living with CCCs. It describes and characterises CCCs and includes a discussion regarding the burden of chronic disease.

Internationally, people living with CCCs are considered vulnerable healthcare users because

[CCCs] kill 40 million people each year, equivalent to 70% of all deaths globally. 15 million of all deaths attributed to [CCCs] occur between the ages of 30 and 69 years (WHO 2015).

The global burden of disease has moved away from communicable to noncommunicable diseases, and from premature death to years lived with disability (Murray, C et al. 2013). Noncommunicable diseases, now commonly referred to as chronic diseases, cannot be transmitted from person to person and are permanent, generally insidious, and unpredictable. The WHO (2015) refers to four main types of chronic diseases: cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes.

In Australia, mental health and musculoskeletal disorders have been added to the four main types of chronic disease defined by WHO. This adds to Australia’s burden and to the challenges for healthcare provision because of the personal, social, and

economic impact of these conditions (AIHW 2014). Diverse regional factors such as differences in demographics, disease patterns, an ageing population, difficulties with the supply and distribution of the health workforce, and the question of how best to balance funding of health services (Armstrong et al. 2007) further emphasise the importance and need for understanding of the local burden of disease. This can be achieved by engaging, quality healthcare provision, which promotes connection, communication, and collaboration between healthcare users and healthcare providers (Huber 2011; Murray, C et al. 2013; WHO 2015).

### **2.2.1 Description and characteristics of complex chronic conditions**

The Australian Government (2016c) describe CCCs as being, or expected to be, present for six months or longer and to have permanent effects. The characteristics of CCCs

[A]re complex in cause and effect, have multiple risk factors, have a long period before diagnosis, are prolonged, and cause functional impairment and disability (ADH 2016c).

This is in contrast to acute or episodic conditions, which resolve completely within a short time period. CCCs are the result of a combination of genetic, physiological, environmental, and behavioural factors (Martin & Sturmberg 2009; Murray, E et al. 2005; Sevick et al. 2007; WHO 2015). They incorporate multiple morbidities, defined in this thesis as the coexistence of two or more chronic conditions where one is not necessarily dominant. CCCs require the attention of multiple healthcare providers and the provision of facilities including community and home-based care (Martin & Sturmberg 2009; Murray, E et al. 2005; Sevick et al. 2007).

Although the emphasis that a person with CCCs places on their illness can fluctuate daily (Greenhalgh et al. 2015), and although most present with clinical variability and fluctuating symptoms, many risk factors for different CCCs are similar, as are the everyday concerns of people living with CCCs, their families and communities. For example, these concerns can include behavioural changes, the social and emotional impact of symptoms, disabilities, multiple medications, and long-term interactions requiring a variety of healthcare provision (Martin & Sturmberg 2009; Wagner & Groves 2002).

### 2.2.2 Burden of complex chronic conditions

Internationally the personal and economic burden of CCCs is steadily increasing (Martin & Sturmberg 2009; McDonald, J et al. 2004; WHO 2015). Despite the wealth of evidence demonstrating avoidable risk factors, CCCs are now among the most common and expensive illnesses (AIHW 2014; WHO 2015).

The AIHW (2013a) and AIHW (2016) consistently report chronic diseases: as the leading causes of death and disability, accounting for 61% of the total burden. Approximately one-half of all Australians have one chronic disease and an estimated one in four have at least two chronic health conditions. These conditions are caused by multiple factors including, but not limited to, genetics, lifestyle, and environment. It is predicted that CCCs will become more common as the population ages, diagnosis improves, and risk factors increase.

The AIHW (2016) identifies six chronic conditions that create the greatest personal and economic burden: cardiovascular diseases, cancers, chronic respiratory diseases, diabetes, mental health disorders, and musculoskeletal conditions. These conditions put significant pressure on healthcare provision in terms of morbidity, mortality, and healthcare costs. Thirty-one per cent of CCCs could be prevented or are amenable to preventative lifestyle changes.

One in five Australians aged over 45 years now live with more than one chronic condition, and the proportion increases with age (AIHW 2016). However, as demonstrated in Table 1, the largest numbers of people living with CCCs are under 65 years old.

**Table 1. AIHW, analysis of the 2004-05 National Health Survey (2013c)**

Proportion (%) of chronic conditions reported, by age group, 2004-05					
Number of chronic conditions	0–14 years	15–24 years	25–44 years	45–64 years	65+ years
Two	0.8	1.9	3.8	14.1	26.7
Three		0.3	1.1	5.1	15.3
Four			0.2	1.4	5
Five or more				0.5	2.6

CCCs are co-occurring and long-term, without an easily definable beginning, middle, or end. They are transitional and unpredictable, because any intervention can lead to an unintended consequence. Understanding and changing the behaviour of such

complex dynamic systems requires complete appreciation, consideration, and understanding of the person's experience, disease patterns, influences, and constraints (Martin & Sturmberg 2009). In Australia CCCs do not affect only older populations, which emphasises the growing long-term, personal, and economic burden of CCCs.

## **2.3 RURAL HEALTH**

This section describes and discusses rural health in Australia, in the context of: healthcare provision, the demonstrable need to provide these populations with appropriate resources, and health in Tasmania.

Similar to international observations, the health outcomes of rural Australian populations are poor. The environment affects these populations because of their inadequate access to primary and specialty healthcare provision, education, employment, and income (AIHW 2016; eHealth Initiative 2012).

People living in rural Australia bear a disproportionate burden of CCCs. Health, illness, and disease occur regularly in a personal context. Individuals are not only affected by the nature of their underlying condition, they are also affected by the external environment, their emotional and financial abilities to cope, their family's ability to care for them, the nature and dynamics of the local community, and their access to quality healthcare provision (Sturmberg 2014).

Rural populations are defined as vulnerable populations because they are socioeconomically disadvantaged and include minority groups such as those living with CCCs and the elderly (AIHW 2016; eHealth Initiative 2012). This is explained partly by the fact that they live in geographically isolated areas and lack easy access to both quality healthcare provision in emergencies and to regular preventative, primary, and specialty healthcare. Further, this population may lack reliable means of transportation to healthcare provision, receive less education, experience difficulties with language barriers (including colloquial versus professional language), and have diverse cultural beliefs and limited financial resources. Rural populations are considered to have lower health literacy and be more likely to engage in high-risk health behaviours, such as over-indulgence in alcohol, tobacco use, lack of physical activity, and poor eating habits (Greenhalgh 2015; Homko et al. 2008).

All high-risk health behaviours increase a person's chance of developing or aggravating CCCs. Lower health literacy in vulnerable healthcare users may mean that they have a less accurate perception of the risks associated with CCCs and are less inclined to discuss social and emotional issues with their healthcare providers. A lack of recognition and effective management of their CCCs potentially increases the mental and emotional burden of coping for the person, their family, and their community. Education about improving health behaviours and the prevention, treatment, and management of CCCs are an essential part of healthcare provision to vulnerable populations (Charmaz 1983; Homko et al. 2008; Pefoyo et al. 2015; Roland & Paddison 2013; Wan, Vo & Barnes 2012).

Healthcare provision in rural Australian communities is complex, and its frequent isolation from comprehensive public, primary, and specialist healthcare provision further widens disparities in care. Although the numbers of appropriate full-time equivalent healthcare providers in such areas are continually assessed, there remains a need for more efficient access to a broader scope of contemporary quality healthcare provision and digital innovation (NRHA 2013).

People living with CCCs are disproportionately represented in rural communities. The need to provide this vulnerable population with appropriate quality healthcare resources and to create continuous, consistent healthcare user/provider communication and education, requires the development of new skills and models of healthcare provision for the person living with CCCs and also their family, community, and healthcare providers. Quality healthcare provision that engages and incorporates people living with CCCs requires the implementation of contemporary models of healthcare provision. However, many healthcare users and providers are either not acquainted with these or do not use them well. Therefore, continuous education for healthcare users and providers and the development of new initiatives are needed (eHealth Initiative 2012; Greenhalgh et al. 2009; Project Integrate 2016; Whetton 2005).

Tasmania lies off the south-east corner of the Australian mainland. It is an isolated island and Australia's smallest state, with a population of approximately 500,000 (ABS 2016b). Tasmania is mostly classified as outer regional or remote (ABS 2011). Hobart, the state's business and administrative capital, is Tasmania's only metropolitan city. The state consists mainly of small rural towns and villages spread

across an eclectic range of locations from rural farming areas to those bordering urban areas. The rural communities accommodate a diverse range of people, personalities, and lifestyles; each town and village has distinct cultural attributes. Tasmania experiences rural health issues similar to those of the rest of Australia, but their experience are made unique by state-specific geographical and socioeconomic factors. Healthcare planning and provision for Tasmanian rural areas requires an approach that recognises their distinctive histories and unique values, including how they relate to the broader Tasmanian and national contexts.

The Department of Health and Human Services (DHHS) (2013) reported that Tasmanian socioeconomic status was below the national level. In 2011, the unemployment rate and the proportion of people living below the poverty line in Tasmania were the highest of any state in Australia. The ABS (2016a) confirms that this situation persists. Health-related behaviours in Tasmania reflect the overall effect of a lower socioeconomic status: a high prevalence of continued smoking, alcohol consumption, obesity, poor nutrition, and low physical activity levels. This low socioeconomic status and persistent participation in avoidable risky behaviours combined with an ageing population increases the incidence of CCCs.

Rural areas of Tasmania are comparable to the rest of rural Australia. They report a higher prevalence of risk factors and worse health outcomes than urban areas (DHHS 2013). These factors ultimately result in an increased prevalence of CCCs and a lack of success in managing CCCs by individuals and communities (AIHW 2013c).

## **2.4 SHARED DIGITAL HEALTH RECORDS**

This section provides a background to SDHRs. The section provides a historical overview, a description and discussion of digital health record systems, characterises the elements of digital health, and finally discusses the role of a SDHR.

The appropriate incorporation of a SHDR into healthcare provision has the potential to provide a complete, real-time, digital version of a person's paper health records, with the added benefit of a personal perspective. A SDHR allows information to be instantly and securely available to authorised users. Over the next decade, SDHRs have the potential to transform the way healthcare is communicated and provided.

### 2.4.1 Historical overview

Hippocrates developed the first known medical records in the fifth century B.C. so that information could be transmitted to other physicians. In the 1960s, doctors began to openly acknowledge, where in some complex situations patients' complete health histories would be beneficial, they were not accessible (Weed 1964, 1969).

There is evidence that there are increasing numbers of problems associated with paper-based health records (Burnum 1989; Hershey, McAloon & Bertram 1989). For example, storage problems, lost or misfiled records, duplication of effort, incomplete records, bad handwriting, and writing errors in records. These problems make decisions about treatment and ensuring the quality of healthcare challenging, inefficient, and at times dangerous (Almutairi 2011; Greenhalgh et al. 2009; Young et al. 1998).

In principle, a person's health record should be accessible, coordinated, and include information about the care provided by multiple healthcare providers. It should also incorporate population-based information; e.g., immunisation and vaccination schedules and results of routine cervical and bowel screening tests (Almutairi 2011). Traditional paper-based patient records have long been impractical and are unable to provide these functions fully (van der Lei et al. 1993).

The idea that healthcare users should have access to and ownership of their personal health records is not new. It has long been acknowledged that healthcare users would benefit from viewing their records and should be able to take them home (Coleman 1984). Research that involved giving healthcare users their medical records to read was conducted more than 30 years ago (Baldry et al. 1986). In other countries, healthcare users are allowed to inspect and request copies of their health records (McQuoid-Mason 1996). For example, in 1998 all member countries of the European Union Data Directive enacted legislation allowing healthcare users to access their medical records (Eysenbach & Jadad 2001). The need for the availability of comprehensive health information, whenever and wherever required, has favoured the storage of patients' health information as digital health records (Lin 1999). The requirement for continued improvement in the quality of healthcare provision remains the motivation for implementation of a SDHR (Kopetsky 2011).



All healthcare systems have complex sociocultural implications. This means that they are complex adaptive systems, which require deeply rooted components that are multifocal, nonlinear, interrelated and interdependent, social and technical. A change in one part of the system affects other parts, further increasing the complexity of healthcare provision. The introduction of IT into complex healthcare systems has implications that require cultural changes for all stakeholder roles (Leykum et al. 2007; Martin & Sturmberg 2009; Muhammad, Teoh & Wickramasinghe 2012).

Despite the evidence suggesting that a lack of appreciation of and attention to fundamental complex sociocultural implications leads to the failure of any new initiative in healthcare systems (Cresswell & Sheikh 2009), IT health initiatives continue to be motivated by politics rather than by the needs of healthcare users or providers (Showell 2011). From the outset of such initiatives, this results in alienation of stakeholders (Showell 2011; Showell & Turner 2013).

Healthcare is an information-rich industry. Countries in the Organisation for Economic Cooperation and Development (OECD) continually face challenges in the delivery of quality healthcare provision. The recognition that digital health technology is expanding provides opportunities to explore this area in depth (Briones 2015), and the use of digital health technology has implications for all stakeholders. There is a need for a comprehensive transitional SDHR that can handle not only multiple layers of diverse information but also improve the flow of this information between all stakeholders (healthcare users, healthcare providers, and government agencies).

A comprehensive, transitional digital health system would provide opportunities to improve the quality of healthcare and ultimately improve health outcomes. SDHRs have the potential to play a significant role in all current healthcare reform agendas. It is for these reasons that the Australian government chose to build MyHR (Muhammad, Teoh & Wickramasinghe 2012).

### 2.4.2 Description of digital health record systems

The umbrella term ‘digital health’ incorporates, but is not limited to, areas such as eHealth<sup>8</sup>, mobile health, telehealth and telemedicine, health information technology, wearable devices, and personalised digital medical devices (Scholz 2016). The term eHealth came into use in the year 2000 (Pagliari et al. 2005), and a systematic review by Hans et al. (2005) identified 51 definitions of eHealth. ‘eHealth’ has been used to describe health and healthcare activities carried out with the assistance of ICT, particularly the internet, that support healthcare provision, as well as personalised health systems for healthcare users (Standards Australia 2016; WHO 2016a). The lack of agreement and standardisation of the meaning of eHealth has caused confusion among stakeholders (Pagliari et al. 2005; Showell & Nohr 2012; WHO 2012). For the purpose of this research, we defined the following relevant components of digital health records within a common and agreed digital health space: electronic medical records (EMR), electronic health records (EHR), and personal health records (PHR). For clarity and comprehensiveness, the WHO Global Observatory for eHealth Series (2012, p. 11) offers the following definitions.

**EMRs** are clinically focused, contain clinical records and are generally held within a single clinical establishment.

An electronic medical record (EMR) is a real-time patient health record with access to evidence-based decision support tools that can be used to aid clinicians in decision-making. The EMR can automate and streamline a clinician’s workflow, ensuring that all clinical information is communicated [within a single establishment]. The EMR can also support the collection of data for uses other than clinical care, such as billing, quality management, outcome reporting, and public health disease surveillance and reporting (WHO 2012, p. 11).

**EHRs** contain personal health information acquired from one or more healthcare provider establishments. They have the ability to be shared across a broad range of healthcare providers.

The electronic health record (EHR) is a longitudinal electronic record of patient health information generated by one or more [clinical] encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems,

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<sup>8</sup> There are a number of ways electronic health is written, for example eHealth, ehealth, e-health and e-Health. I have chosen to refer to electronic health, in this thesis, as digital health. However, for the sake of reference accuracy, I have retained the original choice of depiction of the term in all quotations and references to publications.

medications, vital signs, past medical history, immunizations, laboratory data, and radiology reports. The EHR automates and streamlines the clinician's workflow. It has the ability to generate a complete record of a clinical patient encounter – as well as supporting other care-related activities directly or indirectly via an interface – including evidence-based decision support, quality management, and outcomes reporting (WHO 2012, p. 11).

**PHRs** are a universally accessible, life-long tool, owned by the healthcare user and shared with all their identified healthcare providers.

It is a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and eHealth tools. The PHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains (WHO 2012, p. 11).

### 2.4.3 Characterising elements of digital health

When describing eHealth, Eysenbach (2001) presented the 'e' in eHealth not as electronic but as 10 essential 'characterising' elements. These are displayed and summarised in Table 2, which is adapted from Eysenbach (2001, pp. 1-2). These 10 elements suggest that quality digital healthcare provision is, or should be, understood as a contemporary, dynamic provision or enhancement of healthcare provision supported by digital technology. Digital healthcare provision aims to allow an active role for all users. An active role means that all users are informed, have choices, have access to information, and are actively involved in their healthcare decision-making processes (Eysenbach 2001).

The concept of digital healthcare provision should be encouraged by accepting and supporting the ideal of the informed healthcare user and their desire to engage, rather than by considering them as 'threatening intruders trespassing into a forbidden zone' (Eysenbach & Jadad 2001, p. 6). Further, real-time information about the treatment decisions made by healthcare providers could allow continuous feedback to help improve healthcare user outcomes. Equally, real-time information provided by the healthcare user could provide continuous feedback about their needs to the healthcare provider, helping to better inform quality decisions about delivery of healthcare provision, such as the transitional mix of healthcare provider skills required during any healthcare user's transitional journey (Moberly 2017).

**Table 2. Ten essential ‘characterising’ elements of eHealth**

1	Efficiency	Avoiding unnecessary duplication of diagnostics and therapy by the more active involvement of the patient
2	Enhancement of the quality of healthcare provision	The patients have the ability to communicate with and compare different healthcare providers and specialists
3	Evidence-based health	Proven science and evaluation form the basis of healthcare interventions
4	Empowerment	Universal, equitable person-centred healthcare provision. Patient choice, collaboration, quality, participation with better access to patient records and healthcare information on the internet. Griffiths et al. (2007) claim that it would be unethical for patients not to be involved in decisions about their health.
5	Encouragement	Encouragement of the relationship between the patient and the health professional develops shared decision-making and endorses equality in the relationship.
6	Education	Education of healthcare professionals and patients is essential.
7	Enabling	Enabling information exchange and communication facilitates cohesive communication between different healthcare establishments and consumers
8	Extending	Extending the scope of healthcare: patients can use the internet to access and obtain a range of online healthcare services, potentially at a global level.
9	Ethical challenges	The patient–professional interaction poses new challenges for online professional practices, informed consent, and privacy and equity issues.
10	Equity	Equity of healthcare is one of the promises of e-health, but at the same time there is a considerable threat that e-health may broaden the gap between the ‘haves’ and ‘have-nots’. (Eysenbach 2001; Eysenbach & Jadad 2001).

Like healthcare users, healthcare providers require skills in the use of ICT, experience or familiarisation with sources of high-quality information (Shepperd, Charnock & Gann 1999), and confidence in the use of digital health tools, to allow them to engage competently in digital shared decision making. By characterising the ‘e’ in eHealth as 10 essential elements, Eysenbach (2001) challenges paternalistic, siloed models of continuing healthcare provision, and provides an alternative context that empowers all stakeholders and informs them of the practical possibilities of the delivery of contemporary shared digital healthcare provision.

#### 2.4.4 The role of a shared digital health record

Any SDHR is only as good as its commissioners, designers and users (Almutairi 2011). At any one time, multiple stakeholders from multiple sources may require access to a person's SDHR, to support the many roles required to provide quality healthcare. Heard et al. (2000) identified and ordered the roles of a SDHR; we adapted and summarised this information, which is displayed in Table 3.

**Table 3. Roles for the a shared digital health record**

Supports healthcare user involvement	<ul style="list-style-type: none"><li>• Protects personal privacy</li><li>• Allows healthcare users to view information</li><li>• Accommodates healthcare users' self-management</li><li>• Ensures accountability of healthcare providers</li></ul>
Supports healthcare users	<ul style="list-style-type: none"><li>• Forms the basis of a historical account</li><li>• Anticipates healthcare needs</li><li>• Describes preventative measures</li><li>• Identifies deviations from the anticipated trend</li><li>• Accommodates decision support</li></ul>
Supports communication	<ul style="list-style-type: none"><li>• Supports continuing care and case management</li><li>• Accesses medical knowledge databases</li><li>• Coordinates reports</li><li>• Support electronic data interchange and email generation</li><li>• Enables record access when and where required</li><li>• Supports selective retrieval of information</li></ul>
Supports management and quality improvement	<ul style="list-style-type: none"><li>• Enhances the efficiency of healthcare providers</li><li>• Facilitates management tasks</li><li>• Demonstrates and improves cost-effective practice</li><li>• Accommodates succession planning</li><li>• Provides a legal record of events</li></ul>
Supports population healthcare	<ul style="list-style-type: none"><li>• Supports policy development</li><li>• Provides evidence to support development and evaluation programs</li></ul>
Supports enquiry and learning	<ul style="list-style-type: none"><li>• Supports research</li><li>• Assists with audit</li><li>• Supports education.</li></ul>

The intention of any SDHR should be to support the delivery of person-centred healthcare and, where required, to facilitate the transition of complex healthcare needs, including the complexity of communications between the healthcare user, their multiple healthcare providers, and the healthcare system. The literature includes these under the umbrella of quality health outcomes: equity, efficiency, and quality of care (Institute of Mitnick, Leffler & Hood 2010; Muhammad, Teoh & Wickramasinghe 2012; Tang 2003).

Describing, characterising and contextualising a support role for a SDHR clarifies its role in engagement and facilitation of the delivery of quality healthcare provision.

The adoption of a relatively new concept, MyHR, requires all stakeholders to develop awareness, acceptance, skill, and an integrated understanding of the descriptions, characteristics, and roles of its components. Recognising and applying these elements early in the experience of and engagement with MyHR may offer the essential resources to equitably equip all stakeholders equitably.

## **2.5 MY HEALTH RECORD**

This section discusses international approaches to the implementation of shared digital health systems and reviews the position of MyHR in the digital health system.

Australia committed itself to the delivery of digital healthcare as a major response to the changing nature of quality healthcare and the challenges faced in its provision. One significant digital health initiative was Australia's development and rollout of their SDHR, MyHR. However, there has been concern about this program from the beginning. There is evidence that its implementation was politically motivated rather than being the result of a clearly articulated implementation strategy, and it has ignored the context and complexity of healthcare provision (Almond, Cummings & Turner 2013).

In 2010 the Australian Government approved the development of the MyHR system (then titled the PCEHR) to be delivered by July 2012, and allocated funding of \$466.7 million. The National Electronic Health Transition Authority (NEHTA), which was contracted to manage the program on behalf of the Department of Health and Ageing (DOHA), claimed that:

[T]he PCEHR will greatly enhance both the quality and the timeliness of available healthcare information, delivering substantial benefits to consumer, healthcare provider and the healthcare system as a whole (NEHTA 2012a).

As stated in section 1.1.3, the lack of a clearly articulated implementation strategy meant that the roll out of the MyHR encountered problems from its launch. By 2013, the estimated spend had ballooned to \$1.5 billion and only about three and a half per cent of the total population had registered (NEHTA 2013). That year, the newly appointed health minister ordered a review of the project (NEHTA 2013b). Healthcare user interests were, once again, neglected in the review (Spriggs 2013): the users' requirements of the system were never investigated or valued. The

designers again built into the system their assumptions about the needs of healthcare provision (Almond, Cummings & Turner 2013).

In mid-2016, continued low registration levels and little evidence of engagement with MyHR persuaded the Australian Government to trial ‘opt-out’ registration. Most healthcare users in Northern Queensland and the Nepean Blue Mountains were automatically registered for MyHR (ADH 2016a). The Government assumed that if registration were generated on behalf of the healthcare users and providers, their engagement would automatically follow.

Meaningful engagement with any SDHR should be based on representation and consideration of the requirements of all stakeholders, to ensure that it is usable and useful for the maximum number of users (Aarts, Doorewaard & Berg 2004; ePractice Editorial Team 2013; Greenhalgh et al. 2010a; Jones et al. 2008; McDonald, K 2013). Consideration of the requirements of vulnerable healthcare users was considered a prerequisite for the successful implementation and subsequent evaluation of MyHR, yet there is no evidence that these requirements were accommodated (Almond, Cummings & Turner 2013, 2016).

### **2.5.1 International approaches**

The current approach to MyHR implementation lacks transparency and deliberation, creating indifference to its attempt to tackle the reality of Australian healthcare provision (Almond, Cummings & Turner 2017). A review of the evidence regarding international approaches toward implementation of SDHRs has identified some crucial elements. Although the SDHRs implemented in England and the United States were identified as exemplars, closer examination reveals points of failure arising from their approach, including programs that are too large and ambitious and that try to accomplish too much, too-rapid implementation, and systems that rely heavily on commercial companies that make compatibility and interoperability virtually impossible. Therefore, these approaches should not be replicated (Greenhalgh et al. 2010b; Jolly 2011).

Alternatives that Australia could consider include the experiences of successful implementation of SDHRs in smaller populations such as in the Netherlands, Denmark, Estonia, and Scotland. The Netherlands is an example of a user-focused SDHR approach that provides lessons about the challenges, achievements, and

critical factors involved in successful implementation (Aarts, Doorewaard & Berg 2004). They suggest that it is not sufficient to analyse routines to identify how digital technology might be implemented, and that both technology and routines must be altered to successfully implement any digital technology system (Aarts, Doorewaard & Berg 2004; Greenhalgh et al. 2010a).

Denmark, Estonia, and Scotland, all well advanced in development of their SDHRs, provide examples of how stakeholder co-operation and collaboration can deliver digital health outcomes acceptable to all. They recommend focusing on a simple, basic design, recognising that increasing the level of complexity does not bring a corresponding increase in benefits (ePractice Editorial ePractice Editorial Team 2013; Greenhalgh et al. 2010a; Jones et al. 2008).

A review of international approaches to implementation of SDHRs and their successes and failures clarified that it is not appropriate to consider any one system entirely transferable, because each country has a number of contextual considerations for the provision of healthcare. For Australia, a SDHR organised along centralised lines is unlikely to meet the basic requirements: Australian remuneration structures are a diverse mix of federal, state, regional, and private funding, the population is relatively small compared with the tyranny of distance, and regional diversity together with varying demographics, disease patterns, and ageing population profiles provide further challenges (Armstrong et al. 2007). Australia needs to review its priorities for MyHR in the context of its own quality healthcare provision needs, and to identify alternative approaches to their solution.

What Australia can learn from the evidence is that successful implementation of MyHR must recognise the importance of conceptualising and framing the critical factors. These factors include, but are not limited to, an assessment of the anticipated effects on all stakeholders, an understanding of the changes required to prepare for new healthcare provision practices balanced against the benefits of existing practices, the requirements for the design of the system interface, and the need to build in contingency plans to cope with the unexpected (Bardach & Cabana 2009; Beasley, Holden & Sullivan 2011; Bonner et al. 2010; Campbell, E et al. 2009; Campbell, E et al. 2006; Cresswell, Worth & Sheikh 2012; Greenhalgh et al. 2010b; Harman et al. 2012; Holden 2010).

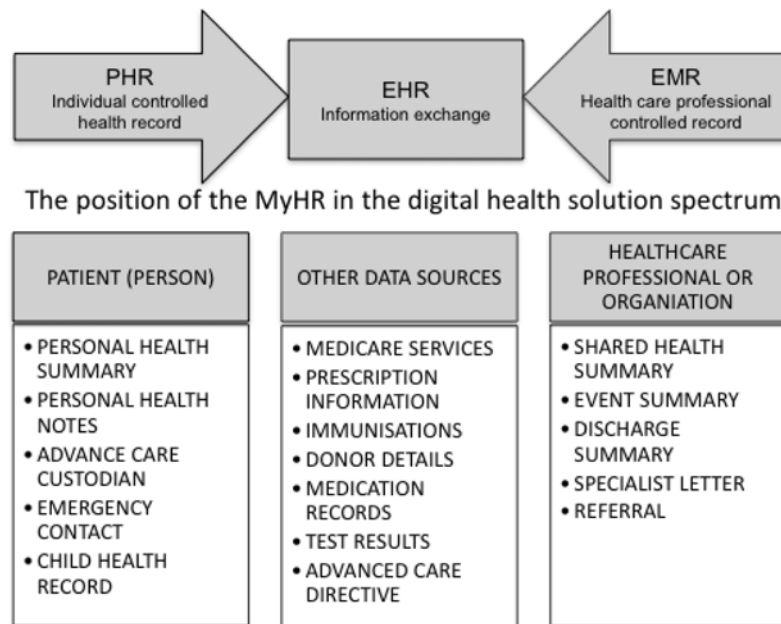


The evidence suggests that it is not SDHRs themselves that bring about quality healthcare provision, but the changes that they facilitate across the quality healthcare provision of which they are a part (Beasley, Holden & Sullivan 2011). Achieving benefits from SDHRs depends on an understanding of the complex sociocultural implications and changes required of all stakeholders (Bardach & Cabana 2009; Beasley, Holden & Sullivan 2011; Campbell, E et al. 2006; Greenhalgh et al. 2010b; Holden 2010; Muhammad, Teoh & Wickramasinghe 2012; Pettigrew 2010). What has not been considered or communicated in Australia is that MyHR implementation changes communication patterns.

MyHR provides opportunities for different and innovative ways of thinking about the methods of delivery of quality digital healthcare provision. MyHR is not a stand-alone system, and should not be viewed as such. Implementation of MyHR is not a linear process with predictable outcomes and deliverables. The evidence from England and the United States and the experiences of the Netherlands, Denmark, Estonia, and Scotland can assist in the development of approaches to support the implementation of MyHR, but should not be regarded as directly transferable to Australia (Almond, Cummings & Turner 2013).

### **2.5.2 My Health Record's position in digital health systems**

The design of MyHR is based on shared responsibility. It integrates three web-based portals: personal health records (PHR) and two clinical electronic health record systems (EHR and EMR). As depicted in Figure 2, MyHR traverses a PHR (owned, managed and shared by the healthcare user) an EHR, and an EMR (healthcare provider health records).



**Figure 2. The position of the MyHR in the e-health spectrum (NEHTA and DHA, 2011)**

Healthcare users have access to all three portals, the PHR, EHR and EMR. Healthcare providers have access to the EMR and EHR and partial access to the PHR (e.g., details of the advanced care custodian, emergency contact, and the child health record). By using a personal or professional ‘unique identifier’, MyHR acts as a hub to link personal, hospital, clinical, pharmaceutical, and Medicare systems (DHA 2009). MyHR captures information from multiple systems and presents it in a single view with an aim of supporting quality healthcare provision (NEHTA 2012a).

MyHR can facilitate quality and environmentally friendly healthcare provision (NEHTA 2012a). It has the capability to deliver integrated, person-centred healthcare by enabling connection, communication, and collaboration, protecting confidential information, and permitting only registered health providers to access personal health information (for example excluding reception and administrative staff and transcription services). MyHR also has the potential to reduce the effect of storage problems, lost or misfiled charts, duplication of effort, ineffective data management, errors because of poor handwriting (Almutairi 2011; Greenhalgh et al. 2009; Young et al. 1998), travel, and unnecessary appointments, and redefines the roles of administrative and reception staff.

MyHR can provide a conduit between evidence-based practice and person-centred medicine. Using the concept of person-centred care from a complex adaptive system perspective, MyHR, when used to engage, collaborate, and communicate, should be

considered an unequalled opportunity to explore the gaps and challenges of equitable healthcare provision for those working and living with CCCs.

## 2.6 PARTICIPATORY RESEARCH EVALUATION METHODS

This section describes, discusses, and compares three participatory evaluation methods: CBPR, participatory design (PD), and user-centred design (UCD). The comparison emphasises that CBPR is the only approach that includes a continuing partnership throughout the research and enables the researcher to engage as a trusted member of the research community, which in this case includes the intended users of MyHR, although not all partners may be intended users.

Greenhalgh et al. (2015) suggested that to reduce biases in the delivery of evidence-based practice, research should embrace the involvement of healthcare users, make systematic use of personally significant evidence, take a more humanistic view, and address unequal power dynamics in the research and support communities. These authors also emphasise that care must be taken not to conflate when adopting participatory methodologies, which could result in framing ‘person-centred’ through a research lens and reducing it to a series of results, the significance and context of which become lost, devalued, or overlooked.

Community based research is based on a participatory philosophy (Heron & Reason 1997). The principles of CBPR (Hills & Mullett 2000) can be seen in other participatory evaluation methods, such as PD and UCD (Nohr & Aarts 2010; Unertl et al. 2015). All three approaches (CBPR, PD and UCD) share the objective of incorporating the perspectives and needs of intended end users into health and health technology implementation. However, as illustrated in Table 4, there are differences between the theoretical foundations and community engagement across the research stages of CBPR, PD and UCD.

Iteration occurs during the course of the research in all three approaches (CBPR, PD and UCD), but CBPR is the only approach:

- that enables the researcher to engage as a trusted member of the research community;
- that includes continued partnership and maintenance activities;

- in which the community are the intended users for the technology but not all partners may be the intended users.

**Table 4. Comparison of CBPR, PD and UCD**

<b>CBPR</b>	<b>Problem Definition</b>	<b>Study Design</b>	<b>Needs Development</b>	<b>Data Collection</b>	<b>Data Analysis</b>	<b>Results Dissemination</b>
<b>Community</b>	x	x	x	x	x	x
<b>Researcher</b>	x	x	x	x	x	x
<b>CBPR continued partnership development and maintenance activities</b>						
<b>PD</b>	<b>Problem Definition</b>	<b>Study Design</b>	<b>Needs Development</b>	<b>Data Collection</b>	<b>Data Analysis</b>	<b>Results Dissemination</b>
<b>Intended end user</b>			Limited			Limited
<b>Community</b>	x	x	x	x		Limited
<b>Researcher</b>	x	x	x	x	x	x
<b>UCD</b>	<b>Problem Definition</b>	<b>Study Design</b>	<b>Needs Development</b>	<b>Data Collection</b>	<b>Data Analysis</b>	<b>Results Dissemination</b>
<b>Intended end user</b>			Limited	x		Limited
<b>Community</b>	x	x	Limited	Limited	Limited	Limited
<b>Researcher</b>	x	x	x	x	x	x

In PD, the researchers usually control the research design and the dissemination of results, although the end users collaborate in research implementation (Nohr & Aarts 2010). In UCD, the researchers normally lead the entire effort from research design to dissemination of results (Ritter, Baxter & Churchill 2014). In contrast, CBPR is an inclusive research model that is defined by purposeful engagement among researchers and intended end users throughout all stages of the research (Israel, B et al. 2003). The level of engagement through CBPR can alter how health and health technology innovation is implemented and translated into wider practice (Unertl et al. 2015).

CBPR was identified as the most suitable research methodology for this research because of its collaborative processes that involve a community who are not professional researchers, while enabling the researcher to engage as a trusted member of the research community. The methodology acknowledges the unique strengths each partner brings (Bergold & Thomas 2012; Minkler 2005; Rogers &

Veale 2000). This research was prompted by and important to the rural community and had the aim of combining knowledge and action to improve community healthcare provision and reduce health disparities.

From a methodological perspective, it has been said that knowledge created without the active participation of all partners can only be partial knowledge (Cook 2012; Somekh 2002). The principles of CBPR (Hills & Mullett 2000) are based on the assumptions that:

- genuine partnership means co-learning: academic and community partners learn from each other;
- research efforts include capacity-building: in addition to conducting the research there is a commitment to community partners' learning;
- findings and knowledge should benefit all community partners;
- CBPR involves long-term commitments to effectively reduce disparities (Israel, B et al. 2003).

Adopting these principles provided the researcher and research partners with fundamental principles to guide actively the building and maintenance of trust-centred relationships toward the goal of successful experience of and engagement with MyHR. The level and nature of this relationship is a characteristic of other research approaches, but is a critical element of CBPR (Unertl et al. 2015).

People living with CCCs in a rural community became actively involved as a research community throughout the research; their experiences and understanding were reflected directly in shaping the research that describes and affects their lives. Recognition of the need to involve and gather first-hand knowledge derived from experience and facts guided by discussion, required researching with the community in a real-world context. This process assisted in the development and growth of trust-centred relationships, equity, capacity, and genuine partnerships between the research partners, the community, and the researcher (Israel, B et al. 2003; Unertl et al. 2015).

Facilitating research in a real-world context was considered necessary for building and sustaining trust-centred relationships, which recognised and addressed

communication barriers that may impact the research design, implementation, and analysis. Each contact with the partners and groups was regarded as an opportunity to establish commitment that could inform subsequent research decisions; this was considered important to sustain engagement. Adopting the principles of CBPR embraced the building of genuine partnerships and capacity, and effectively empowered rural community involvement in the development and delivery of digital healthcare provision.

Identifying with CBPR empowered the researcher to involve the community and reflect their subjective experiences of and engagement with MyHR. This participatory paradigm openly included and acknowledged those who affect and those who are affected by the topic of concern, incorporating their contributions, expertise, shared responsibilities and ownership. In this way the research approach for studying a community in a real-world context avoided power imbalances (Greenhalgh et al. 2015; Hills & Mullett 2000). Table 5, which is adapted from Greenhalgh et al. (2009), provides a summary of the participatory paradigm and CBPR methodology explained as research characteristics. The research methodology is discussed in depth in Chapter 3.

**Table 5. Research characteristics**

<b>Participatory Paradigm</b>	<b>Community based participatory research</b>	<b>The research characteristics</b>
Subjective ontology (assumption about nature of reality)	Co-creation of socially useful artefact through negotiation and sense making	The exploration gathered the partners' understandings and meanings by participation in interactive and cooperative one-to-one and group discussions in their world about their real-world experience of and engagement with MyHR
Extended epistemology (assumption about the nature of knowledge)	Knowledge is subjective and value-laden, and emerges through making, which is a social process requiring shared vision and understanding	During data collection, the partners cycled through iterations of action and reflection: - <i>Phase one</i> , presented the concept of MyHR (presentational knowledge and propositional knowing). - <i>Phase two</i> , the thoughts and experiences of MyHR, began to accumulate (experiential and practical knowing) - <i>Phase three</i> , the partners tested MyHR in their real world, reflecting on their experiences (practical knowing). The engagement with MyHR providing first-hand knowledge (experiential knowing) in relation to MyHR (propositional knowing). Some partners also chose to share their personal experiences of their rural community through photography (presentational knowledge). Using a thematic framework for data analysis allowed the data to resonate the value of an extended epistemology. Hills and Mullett (2000) remind us that the more consistent are the four ways of knowing, the more valid the evidence for practice
Axiology (what is of value)	Fitness for purpose, ownership, engagement discussion	Axiology is related to extended epistemology through practical knowing in each phase of data collection, which provided the partner and the groups with information engaging them in social participation: how to choose, how to be, and how to perform? This was enabling and was

		considered personally and contextually rewarding, improving and changing experiences
Methodology (assumption about what methods will generate best evidence)	Developmental with a focus on social. Measures shared vision values and collaborative outputs	Using CBPR empowered the value of joint responsibility; multiple ways of knowing and more significantly, it recognised and valued the unique knowledge that a rural community contributed to the co-creation of new real-world experience of and engagement with MyHR. Using CBPR allowed a vulnerable community to collaborate and contribute to research debates about the experience of and engagement with MyHR. It focused on a real-world issue, problem solving and change, which provided research evidence that is both contextually useful and relevant to wider establishments.

## 2.7 MODELS OF HEALTHCARE

This section describes and discusses models of healthcare, focusing on a discussion regarding theoretical context, complex adaptive systems, and person-centred care. Identifying a theoretical context provides background and assists the research discussion.

Management of people living with CCCs is now the leading burden facing healthcare provision in developed countries (Barnett et al. 2012; Bayliss et al. 2008; Salisbury et al. 2011; WHO 2015). In Australia, the population is ageing, and more people than ever are being diagnosed and living longer with CCCs (AIHW 2016). A modified model of contemporary healthcare provision is required to reduce the personal and economic burden on people living with CCCs, their families and communities, and healthcare provision.

The literature continues to describe living with CCCs as a deviation from a ‘normal state’ and as ‘illness exacerbations’ that prompt the ‘patient’ to seek care (Carel 2016; Mol 2008; Mol, Moser & Pols 2015). A modified model of quality healthcare provision is required to move away from this paternalistic, inflexible, siloed framework of thinking that is designed for ‘patients’ requiring acute, episodic, and uncoordinated healthcare provision. A contemporary model needs to realise and support the transitional requirements of the person living with CCCs and their physical, psychological, and social needs. It is this complexity that makes informed decision making, engagement, and involvement so challenging, especially for vulnerable communities (Greenhalgh et al. 2015).

Currently, there is a paucity of contextual evidence supporting modified models of healthcare provision for people living with CCCs who require transitional healthcare provision (Greenhalgh et al. 2015; Lenert et al. 2014). Access, engagement,

communication, coordination, and integration with people living with CCCs are essential elements in the process of identifying which of their needs is most pressing and what type of healthcare provision is most appropriate. A contemporary model of healthcare provision is required that includes identifying and supporting vulnerable people who are physically, psychologically, and socially challenged, by guiding them through multiple complex decisions, identifying goals, and pinpointing appropriate actions (Charmaz 1983; Pefoyo et al. 2015; Roland & Paddison 2013).

As previously stated, the increase in prevalence of CCCs can be attributed to the convergence of an ageing population with increased diagnoses and the widespread persistence of lifestyle-related risk factors (AIHW 2016; WHO 2015). However, many CCCs are preventable, or respond more favourably in terms of management and medical treatment, in those persons who choose to adopt healthy behaviours. (NPS 2013).

Living with CCCs should not exclude anyone from achieving an active and healthy lifestyle into older age. However, the presence and persistence of CCCs can make it more difficult to access quality healthcare provision to gain a health benefit (DHHS 2013). In Australia there is an emphasis on the prevention of chronic disease. However, this needs to be balanced by assistance to Australians living with CCCs. For a person living with CCCs, self-management is a lifetime task; they must be personally responsible for their everyday decisions about how to personally manage their illnesses (Lorig & Holman 2003).

The term self-management appeared in the mid-1960s in a book written by Creer, Renne and Christian (1976). The book acknowledges the earlier work of Albert Bandura. Since that date, the term has been widely used in conjunction with CCCs. The term self-management suggests that a person is an active partner in their health management (Creer, Renne & Christian 1976). Today the term is used frequently in CCCs education programs and healthcare provision (Lorig & Holman 2003). However, Val (2015) suggested that the term is outdated and is used with little consideration or interpretation of the requirements of diverse personalities, lifestyles, or cultural attributes, all of which can be considered unique in the context of geography and socioeconomic factors.



One recognised example of a self-management model of care is The Chronic Care Model (Wagner et al. 2001), which is based upon a Cochrane systematic review that synthesised randomised controlled trials and controlled before-and-after studies of different aspects of chronic care (Martin & Sturmberg 2009). This model of care paternalistically labels people living with CCCs as ‘patients’ and recommends that healthcare providers identify their patient’s self-management skills and encourages them to take an active role in their care. However, the model has limitations. First, the terminology ‘patient’ presumes an illness and a decreased ability to make rational decisions, excusing them from responsibility for, or self-management of, their incapacity. Second, rather than being a person-centred, integrated approach to wellness, the framework has in practice been interpreted as a time-limited paternalistic model of acute, episodic, linear, single-disease management delivered in specific settings, which does not take account of the impact of the long-term requirements of a person living with CCCs (Charmaz 1983; Martin & Sturmberg 2009). In reality, CCCs are not a time-limited fixed entity: a person living with CCCs has multiple complex transitional requirements across their life span. Finally, introducing and improving the self-management health behaviours of a person living with CCCs requires a contextual understanding of diverse personalities, lifestyles, individual and cultural attributes, and a long-term commitment to a transitional interactive and interdependent environment (Martin et al. 2011; Val 2015).

For a person to manage their CCCs successfully, they require close, open partnerships with multiple healthcare providers. Understanding and managing CCCs extends well beyond brief episodic review visits to a paternalistic healthcare provider who delivers a siloed model of healthcare. People living with CCCs are responsible for the everyday aspects of their wellbeing, which requires understanding and life-long commitment (Lorig & Holman 2003).

Compliance with self-management programs is poor (DHHS 2013; Val 2015). This has been attributed to a number of factors, especially for physically, psychologically, and socially vulnerable populations. These people often lack the access, resources, and skills to facilitate self-management. Barriers to self-management include:

- the inability to communicate and understand and fulfil instructions regarding medication, or self-management;

- a lack of communication and understanding as to the severity of their condition and how to appropriately manage it;
- a lack of access to an ongoing support infrastructure that is capable of educating and engaging the person living with CCCs about the important aspects of personal management of CCCs, including how and when to take appropriate action (eHealth Initiative 2012).

Traditional self-management programs champion enhanced person-centred education (Wagner et al. 2001). However, many self-management education programs continue to be interpreted and delivered within traditional episodic, linear, single-disease models delivered in specific clinical settings, and are time limited. Healthcare providers have expectations or intentions that a person living with CCCs who completes a pre-designed standard ‘short course’ program will leave the program ‘informed’. This information often does not resonate with what occurs in reality. In reality, the person living with CCCs may have different priorities. The illness as lived will differ from the disease or risk state in a single-disease protocol or guideline (Greenhalgh et al. 2015).

CCCs comprise different stages (simple, complicated, complex and chaotic), which require different interventions to address the changing complex dynamic characteristics of the person’s transitional care needs:

- Simple: people are well, functioning and stable. This stage requires optimising the quality of life and preventing complications and further comorbidities.
- Complicated: there are multiple factors, including physical, psychological, and social factors, which cause comorbidity. This stage requires a balance of self-care and healthcare provision interventions.
- Complex: there are acute or acute-on-chronic exacerbations. Flares occur because of disrupted physical, psychological, and social factors, including self-care and healthcare provision.
- Chaotic: there are multiple dimensions of disruption: falls, loss of self-care control, severe pain, shortness of breath, additional diagnoses, mental health

crises, and additional acute conditions such as influenza, resulting in environmental disruption (Martin et al. 2011; Martin & Sturmberg 2009).

Following a brief ‘prescribed’ intervention, the person living with CCCs is expected to go on to lead an active life with minimal arrangements for episodic ‘follow up’, or intervention from their healthcare providers. This creates a culture of isolation for the person and their families until the next exacerbation occurs, and their CCCs steadily worsen. If personal health management programs are to deliver effective change, there needs to be a change from the linear isolation of traditional ‘self-management’ programs to educating healthcare providers and people living with CCCs about the need for self-organisation, continuous communication, engagement, involvement, and integration with preventative healthcare provision.

Models of healthcare that identify with vulnerable, diverse communities of people living with CCCs and facilitate their engagement, involvement, and integration with their healthcare provision can be more effective in reducing the personal and healthcare-provision burden of CCCs than traditional patient education and out-dated prescribed ‘self-management’ programs (Chin et al. 2001). For a quality model of healthcare provision to work, there needs to be a better understanding of community infrastructure and the development of systems, communication, and healthcare provider training that engage people living with CCCs, their carers, and their healthcare provision (Toomey & Coote 2013). A modified, coordinated community approach is required to implement these elements. Adapting existing healthcare provision models to enhance participation, uptake, and sustainability could facilitate this (Battersby et al. 2003; Bodenheimer et al. 2002; Jordan et al. 2008).

The interaction between a person living with CCCs and their healthcare provision requires a long-term quality approach to their multiple and complex care requirements that ensures appropriate interventions in response to unpredictable changes in CCCs at unpredictable times.

### **2.7.1 Theoretical context**

Accepting healthcare users as agents within a complex adaptive system and adopting a person-centred model of care can embed the capacity and role of MyHR as a contemporary resource and offer new opportunities. For the healthcare user and healthcare provision, these opportunities may be perceived as improved

understanding, communication, collaboration and personal development. However, this requires modifying existing healthcare provision models. The real-world is complex: implementation of any digital health technology requires incorporating ‘different ways of working and thinking with models and tools’ (Petrakaki, Cornford & Klecun 2010, p. 2). Digital health technology cannot be studied in isolation from healthcare provision (Beasley, Holden & Sullivan 2011). Research needs to consider what people say they do, what they actually do, how they translate their beliefs into actions, and how they consider their options.

Identifying a theoretical context provides the background about how the perspectives of people living with CCCs in rural communities relate to their experience of and engagement with MyHR. Viewing healthcare users as agents within complex adaptive systems and adopting a person-centred model of healthcare provision assists the research discussion and supports the key findings as priorities that will enable a positive experience of and engagement with MyHR.

#### ***2.7.1.1 Complex adaptive system***

A person’s health, illness and disease experiences can be tracked over time and referred to by different characteristics: prevention, acute illness, chronic disease, or psychological turmoil (Sturmberg 2013). Healthcare provision and disease transitions vary according to interconnected interactions between a person’s physical, psychological, and social state and healthcare provision. People living with CCCs require continuous awareness of their personal care; adopting and incorporating new technology requires complex interventions that include multifocal, non-linear, components (Leykum et al. 2007; Martin et al. 2011; Martin & Sturmberg 2009).

Complex adaptive systems are defined as collections of many different components (agents) that interact in non-linear ways. A complex adaptive system is characterised by the relationships between the agents and their patterns of interactions (Sturmberg 2014).

A complex adaptive system encourages four dynamic, interdependent characteristics of a healthcare experience:

- *Diverse agents who learn:* people can and will process information and react to changes in information;

- *Interconnections*: non-linear interdependencies including non-verbal communication among agents, and the introduction of new agents into the system;
- *Self-organisation*: order created in a system without clear hierarchical direction;
- *Co-evolution*: the system and the environment influence each other's development (Leykum et al. 2007; McDaniel Jr., Lanham & Anderson 2009).

When viewed separately, the four characteristics that make up a complex adaptive system have different properties to those of the complete system. Understanding the mechanisms underlying one illness does not tell us anything about the person affected by the illness (Greenhalgh et al. 2015; Sturmberg 2014). Therefore, to achieve the four dynamic characteristics of complex adaptive systems as outlined above, a model must have the person at its centre. Though all agents have their local interactions, they also always interact with agents across wider communities. In seamless quality healthcare provision, all agents should focus on healthcare provision from the viewpoint of a healthcare user's experience and needs (Sturmberg 2014).

#### ***2.7.1.2 A person-centred approach***

In the context of this research, a person-centred approach is defined as putting the person (healthcare user) at the centre of their healthcare provision. For example, information should be provided to a person living with CCCs in a format and language that they can relate to and understand fully, thereby enabling them to make informed choices and encouraging them to have as much control over their lives as possible.

Research involving the perspective of the healthcare user is a rapidly emerging interest. However, incorporating a person-centred approach into traditional evidence-based research often conflates identities (Greenhalgh et al. 2015). Firstly, personal nuances can be lost: two or more people, concepts or places that share characteristics may become a single identity. Secondly, a healthcare user may have their problem framed through the lens of the researcher and interpreted as a series of risk-assessment guidelines and decisions about healthcare provision. Finally, these people

can be treated as a disease, commonly managed by a clinically defined ‘patient’s agenda’, without consideration of diverse personal or community contexts or the dynamics of the clinical encounter (Greenhalgh et al. 2015; Sturmberg 2014).

It is challenging to involve healthcare users and person-centred approaches in digital health research, and many digital health system developers minimise this aspect (Arsand & Demiris 2008). Most digital health research continues to focus mainly on healthcare providers in large institutions, who are easier to engage through their administrative hierarchy, rather than on vulnerable healthcare users, who face many burdens in their daily lives and are perceived as reluctant to engage with a new system (Gordon & Hornbrook 2016; Graetz et al. 2016; Kontos et al. 2014; Showell & Turner 2013). Further reasons why healthcare users and, in large institutions healthcare professionals, are not readily involved in digital health research is their interest varies considerably. They are not the ones investing in the digital health systems, the institutions are the customer of the digital health system developers. It may also be leveraged a significant number of healthcare providers do not want healthcare users to have access to their own health record, so there is no incentive for them to get them involved (Eysenbach 2001).

Person-centred digital health tools should be designed to have the ability to increase a healthcare user’s personal understanding of their capabilities and improve their health status and management of their condition (Bandura 1997). Many sustainable, supportive digital health tools espoused as person-centred do not fully realise the potential provided by digital technology, because their developers have not considered the real person’s needs in the real world. The design of digital health tools should ensure that a person’s capabilities are understood and taken into consideration during development and early implementation phases (Arsand & Demiris 2008; Hemsley et al. 2018; Showell & Turner 2013).

For healthcare users, there are four qualities that person-centred digital interfaces require: they need to be multimodal, personally and contextually aware, and adaptive (Sainfort, Jacko & Booske 2002). People living with CCCs, as healthcare users of digital health tools, are likely to be mature adults whose every-day basic tasks need to be considered. These include age and health related changes, functional abilities

such as sensor-perceptual processes, motor abilities, response speed, and cognitive processes (Arsand & Demiris 2008; Czaja & Lee 2002; Hemsley et al. 2018).

Arsand and Demiris (2008) suggest the following approaches toward person-centred research and the use of digital health resources:

- testing the digital health resource in the context of and with people who have a real need for the resource's functionalities;
- using storytelling as an effective way of explaining and garnering how a digital health resource works;
- allocating sufficient time and several meetings; this allows the user to understand the options the digital health resource offers and lets their own creative ideas surface;
- planning for extra time and testing with users; this will ultimately improve the post-intervention data analysis process;
- getting the users to test the digital health tool and log their experiences themselves if at all possible;
- using post-intervention interviews to garner an in-depth understanding of the user experiences;
- consider using groups for comparison and validation;
- selecting the person-centred computer interaction methods that are most relevant for a given context and user.

Digital health system research has involved person-centred approaches with healthcare users to a limited extent. This has been despite repeated evidence that using person-centred approaches to better inform the design development and delivery of digital health systems has the potential to improve acceptance and ultimately health outcomes (Eysenbach 2001; Heard et al. 2000; Hemsley et al. 2018; Lorig et al. 1999; Sainfort, Jacko & Booske 2002; Showell & Turner 2013). Further, early digital health research into the development of shared decision-making tools continued to define the end user as the healthcare provider (Arsand & Demiris 2008).

There is an increasing need to engage and empower healthcare users to play an important role in digital healthcare provision research. There is also a requirement to acknowledge the scarcity of healthcare resources for dealing with ageing populations and the increasing numbers of people living with CCCs. Digital health advances make it possible and affordable to design and implement applications intended for direct use by healthcare users and providers alike. At an economic level, delivering person-centred care from a complex adaptive system perspective can reduce expenditure by better preventing the onset of or better managing CCCs (Sturmberg 2014).

Placing the person, a vulnerable healthcare user, at the centre of their concern should result in a seamlessly integrated digital healthcare system, a digital infrastructure that promotes healthy living and provides support for those in need. Meeting the person's healthcare needs and expectations and helping them to make sense of their experience of CCCs will maintain their dignity and place living with disease within the changing demands of the real world, a complex adaptive system. Therefore, it is crucial to incorporate a thorough exploration of all healthcare user needs, adopting appropriate person-centred approaches to prevent further digital incompatibilities, and to extend and complement the current focus on shared decision-making.

## **2.8 SUMMARY**

This chapter has reviewed the appropriate existing evidence relating to the research domain of vulnerable healthcare users, shared digital health records, and participatory research evaluation methods. The chapter also describes and discusses models of healthcare, providing a theoretical background for the discussion.

In developed countries, chronic diseases are now the most common and expensive illnesses and carry a steadily increasing personal and economic burden. People living with CCCs are considered vulnerable healthcare users. Further, people living in rural and remote areas bear a disproportionate burden of CCCs because they live in geographically isolated areas and lack access to quality healthcare provision. The problem is exacerbated by a lack of reliable means of transportation to healthcare provision, less education, difficulties with language, diverse cultural beliefs, and limited financial resources.



The goal of healthcare provision should be that every person, family and community maintains responsibility for their own wellbeing, is informed regarding their health status, and is educated as to courses of treatment. The evidence suggests that SDHRs can assist in meeting this goal by facilitating improved sharing, integration, and quality of healthcare while reducing the burden on healthcare provision.

However, the evidence also suggests that many SDHRs have been designed and implemented from political motives, and rely too much on commercial companies, designers, or researchers who identify a perceived user need, rather than involving the intended end user: those involved in either receiving or providing healthcare provision. Further, the perceived user needs of SDHRs and their resulting design have focused on meeting the requirements of healthcare providers or healthcare systems, while overlooking the needs of the healthcare user.

To investigate this requires evaluation methods that look beyond experimental or randomised controlled trials toward gathering real-world perspectives of the experiences and engagement with a SDHR. In Australia, there is currently a gap in contextual evidence concerning healthcare provision for vulnerable populations and their experience of and engagement with SDHRs, specifically MyHR. Real-world insight garnered from these populations is required to explore the gap between the desired outcomes and the experience of and engagement with MyHR by those directly affected by and knowledgeable of local community healthcare provision.

The research topic reflected a concern of people living with CCCs in a rural community. Currently there is little contextual, personal, or community knowledge about the experiences of people living with CCCs in rural communities, or the factors that assist or restrict their engagement with MyHR. Evaluating their experience of and engagement with MyHR requires nuanced evidence systematically collected from a particular person and community. Using methodology underpinned by a participatory philosophy and paradigm including the principles of CBPR, focused the research on practical issues by recognising and valuing the knowledge that community members contributed to the co-creation of new knowledge.

Identifying the theoretical context provides a background for how the perspectives of people living with CCCs in rural communities relate to their experience of and engagement with MyHR. Modifying existing healthcare provision models, accepting

healthcare users as agents within a complex adaptive system, and adopting a person-centred model of care, can embed the capacity and role of MyHR as a contemporary resource and offer new opportunities. Viewing healthcare users as agents requiring person-centred care from a complex adaptive system assists the research discussion and supports the key findings as priorities to ensure a positive experience of and engagement with MyHR.

Currently, people living with CCCs in rural Australia continue to access limited healthcare provision that is delivered as narrow, paternalistic, epidemiological research-based ‘patient agendas’. For these vulnerable healthcare users, there remains little contextual evidence that SDHRs support their contemporary quality healthcare provision. This research will explore how people living with CCCs in rural Australia experience and engage with MyHR using a subjective qualitative research methodology.

Chapter 3 presents, describes and discusses the research methodology required to address the research objectives identified in section 1.2.2 and the research questions identified in section 1.2.3.

# Chapter 3: Methodology

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Chapter 3 presents, describes and discusses the research methodology required to address the research objectives identified in section 1.2.2 and the research questions identified in section 1.2.3. The chapter is organised into the following sections:

- 3.1 presents the research philosophy in the context of the experience of and engagement with MyHR of people living with CCCs in a rural community;
- 3.2 presents the participatory paradigm, and is subdivided to describe and discuss the subjective ontology, the extended epistemology, and the axiology;
- 3.3 presents the research strategy and is subdivided to describe CBPR, the community, the research community, the research partners, and the researcher;
- 3.4 presents the research design and is subdivided to describe the recruitment of the partners, the introductory meeting, data collection methods, data collection, and data analysis;
- 3.5 describes and discusses how research validation and rigour were achieved;
- 3.6 describes how the research community ensured that the principles of CBPR were addressed;
- 3.7 describes the ethical considerations of the research;
- 3.8 provides a summary of the chapter and introduces Chapter 4.

## 3.1 RESEARCH PHILOSOPHY

This section introduces the research philosophy in the context of the experience of and engagement with MyHR by people living with CCCs in a rural community. A research philosophy is a belief about the way in which data about a phenomenon should be gathered, analysed, and used. A participatory philosophy perceives a universe as active, animated, and co-creative (Heron & Reason 1997). This research

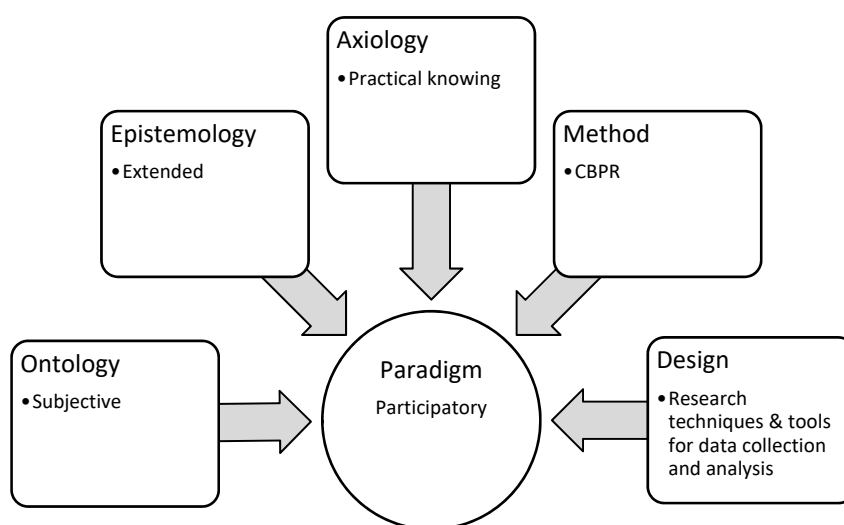
identified with a participatory philosophy that required a subjective, qualitative, analysis that incorporated an axiological component.

The research topic reflected a concern of people living with CCCs in a rural community. There is currently little contextual knowledge about the experiences of people living with CCCs in rural communities, or what assists or restricts their engagement with MyHR. Further, MyHR requires a significant review, because the implementation approaches are failing to engage healthcare users. To explore the gap between those directly affected by and knowledgeable about the local community circumstances and their requirement for meaningful engagement with MyHR requires practical, contextual, insight gathered from the local community.

The exploratory nature of this research required a subjective, qualitative approach based on a participatory paradigm, thus respecting the direct involvement and engagement of the most likely future healthcare users or their representatives, and those who affect and are affected by the problem of concern (Horowitz, Robinson & Seifer 2009; Nohr & Aarts 2010). The participatory paradigm is described in detail in section 3.2.

### 3.2 PARTICIPATORY PARADIGM

This section presents and discusses the participatory paradigm. The participatory research paradigm, depicted in Figure 3, comprises the characteristics of a subjective ontology, an extended epistemology, axiology, CBPR principles, and design based on involvement and co-operative relations between all partners.



**Figure 3. The research paradigm**

Guba and Lincoln (1994, p. 107) stated that a paradigm ‘represents a worldview that defines ... the nature of the world, the individual’s place in it, and the range of possible relationships to that world and its parts’. They continue, discussing four differing worldviews: research positivist, post positivist, critical, and constructivist. These are based on their positions from ontological (‘What is the form and nature of reality and, therefore, what is there that can be known about it?’), epistemological (‘What is the relationship between the knower or would-be knower and what can be known?’), and methodological (‘How can the inquirer ... go about finding out whatever he or she believes can be known about it?’) viewpoints.

Both Mertens (2005) and Heron and Reason (2001) challenge these dominant research paradigms, suggesting a fifth worldview: a participatory paradigm that considers that reality is an interchange between the given universe, a basic reality, and the mind. Participatory researchers consider that interpretive research alone does not adequately address issues of social justice and marginalised people (Creswell 2013). They ‘believe that inquiry needs to be intertwined with politics and a political agenda’ (Creswell 2013, p. 9), and should contain an agenda for reform ‘that may change the lives of the partners, the institutions in which people work or live, and the researcher’s life’ (Creswell 2013, pp. 9-10).

By adopting a participatory paradigm, this research acknowledged and valued the effect of each research partner’s background and experiences on the research by exploring and recognising the social world through the partners’ own perspectives (Mertens 2005; Ritchie & Lewis 2003). Systematically capturing personally significant evidence from a particular community was considered fundamental to the investigation (Greenhalgh et al. 2015). In the context of this research, this would maximise the chance that MyHR meets its important aim: to encourage people living with CCCs to engage with their digital health data, informing and improving their quality of care (van’t Riet et al. 2001).

### **3.2.1 Subjective ontology**

Ontology is an assumption about the nature of reality and what can be known about it (Greenhalgh et al. 2009; Guba & Lincoln 1994). In contrast to conventional research, which makes use of objective quantitative methods and claims to be value free, qualitative approaches place importance on subjectivity (Hills & Mullett 2000).

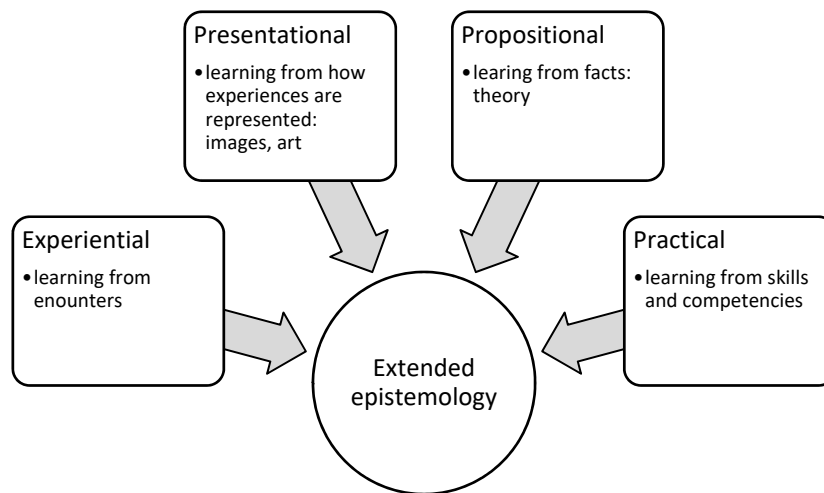
Subjective ontology is described by Abram (1996, p. 124) as ‘underneath our literate abstraction, [there is] a deeply participatory relation to things and to the earth’. Heron and Reason (1997, p. 5) talk about this as participatory, interactive and cooperative:

[To] touch, see, or hear something or someone, does not tell us either about our self, all on its own, or about a being out there, all on its own. It tells us about a being in a state of interrelation and co-presence with us.

The research’s participatory philosophy identified a subjective ontology, which required and guided the exploration to garner the partners’ understandings and meanings of their experience of and engagement with MyHR, in their world.

### **3.2.2 Extended epistemology**

Epistemology is an assumption about the relationship between the knower and what can be known, the nature of knowledge (Greenhalgh et al. 2009; Guba & Lincoln 1994). Conventional science believes in a world that involves the knower adopting an impartial view in order ‘to discover how things really are’; this assumes that the knower and the known are separate, independent units that do not influence one another (Guba & Lincoln 1994, p. 108). However, a participatory paradigm requires an extended epistemology that recognises the requirement to equitably nurture partner researchers, those directly affected by and knowledgeable about the local circumstances that impact health (Horowitz, Robinson & Seifer 2009; Nohr & Aarts 2010). The subjectivity of an extended epistemology recognises and values the importance of the knower participating in the known, allowing the expression of nuance and context through an awareness of four independent and interdependent ways of knowing, how they interact, and the ways of changing the relationships between them. Figure 4 depicts extended epistemology and the four ways of knowing: experiential, presentational, propositional, and practical (Heron & Reason 1997, 2001).



**Figure 4. Extended epistemology, four ways of knowing**

The four ways of knowing are explained as:

*Experiential knowing* (experience) is participatory in nature, an actual meeting with persons, places or things, for example

[Learning from a] direct encounter, face-to-face meeting: feeling and imaging the presence of some energy, entity, person, place, process or thing. It is knowing through participative, empathic resonance with a being, so that as knower I feel both attuned with it and distinct from it (Heron & Reason 1997, p. 6).

*Presentational knowing* (images) is present in experiential knowing, how experiences are represented; for example, through images such as drawing, photographs, writing, dance, art or stories.

*Propositional knowing* (factual knowledge) is a conceptual awareness of something. This type of knowledge can be expressed as statements, facts, or theories

Propositional knowing is knowing, in conceptual terms, that something is the case; knowledge by description of an, entity, person, place, process or thing (Heron & Reason 1997, p. 6).

*Practical knowing* (discussion) combines thoughts and experiences into action (practice)

Practical knowing is, knowing how to do something, demonstrated in a skill or competence (Heron & Reason 1997, p. 6).

### ***Praxis - the relationship of theory to practice***

Before discussing the fourth characteristic of the participatory paradigm, axiology, the role of evidence-based practice for communities and the relationship of theory to practice must be acknowledged (Hills & Mullett 2000). Theory, which explains a

phenomenon, is often considered something that is talked about in academic environments. This gives the impression that it stands alone, separate from day-to-day living. However, Lewin (1947, p. 149) suggests:

[T]here is nothing so practical as a good theory and the best place to find a good theory is by investigating interesting problems in everyday life.

This research cycled through iterations of action and reflection. It considered first-hand knowledge and facts in relation to practical knowing, providing praxis-generated evidence for future practice. Praxis, as a process, places practice within theory rather than applying theory to practice (Heron & Reason 2001). Praxis requires an iterative relationship between theory and practice, and is realised from experience and facts facilitated by discussion. Embracing the relationship between practice and theory in this way gave value to the research approach of studying a community in their real-world context to avoid power imbalances that may have suppressed the community's voice (Greenhalgh et al. 2015; Hills & Mullett 2000).

### **3.2.3 Axiology**

In addition to considering the three defining characteristics of a research paradigm suggested by Guba and Lincoln (1994); i.e., ontology, epistemology and methodology, Heron and Reason (1997, p. 10) suggest consideration of a fourth factor capturing the value question, 'what is essentially worthwhile?' Axiology within a participatory paradigm acknowledges human flourishing, the 'process of social participation in which there is a mutually enabling balance within and between individuals, of autonomy, co-operation, and hierarchy' (Heron & Reason 1997, p. 10). Human flourishing relates to extended epistemology through practical knowing: how to choose, how to be, and how to perform. It is considered a personally rewarding, improving and changing experience.

The intended outcome of the research was to achieve a better understanding of the experiences of and engagement with MyHR and the difference it could make in enhancing the health and wellbeing of a vulnerable community. Axiology encouraged human flourishing by social participation, cooperation, and collaboration, to gather the community's experience of and engagement with MyHR, produce real-world evidence and inform digital health research about personal and community requirements for contemporary healthcare.



The participatory paradigm was perceived as:

- balanced, valuing the contribution that people and community groups and academic digital health research make in the development of knowledge about community practice;
- promoting collaborations between the community and digital health researchers in the design and implementation of the research;
- fostering sustainable effort at a local level that guided the translation of research advances into improved understanding of digital health for all (Hills & Mullett 2000; Somekh 2002).

### **3.3 RESEARCH STRATEGY**

This section introduces the research strategy, and describes CBPR, the community, the research community, the research partners, and the researcher. The research strategy assisted in understanding the motivations behind the methods used by the research community to achieve the research objectives presented in section 1.2.2, and the exploration of the research questions presented in section 1.2.3.

A review of the literature has identified a lack of contextual evidence that SDHRs support person-centred care or improve integrated approaches to rural healthcare provision. The use of subjective qualitative assessment methods, rather than purely data-based information, is vital to understanding the contextual perspective of community values and needs (Sweeny, Pritchard & Yao 2010). However, the literature also emphasises that when adopting participatory methodologies, care must be taken not to conflate, thereby framing ‘person-centred’ through a research lens and reducing it to a series of results (Greenhalgh et al. 2015).

As described in section 3.2, the research identified with a participatory paradigm. CBPR is based on a participatory paradigm, and this research used CBPR as an inclusive strategy to contextually explore the lived experience of and engagement with MyHR by creating a research community by partnering the researcher with people living with CCCs in a rural community. This allowed the research to benefit from the inclusion and acknowledgement of those who affect and are affected by the issues of concern and to incorporate their contributions and expertise as rich data

collected in a natural setting.

The principles of CBPR (Hills & Mullett 2000), as described in section 3.3.1.2, were used to guide the systematic development, implementation, and evaluation of the research. These principles provided a continuous checklist for adherence to the philosophy and principles of CBPR. Importantly, the central assumption of these principles is the full participation of the intended users in the research.

### **3.3.1 Community based participatory research**

CBPR is primarily about people, and is described as collaboration between community and researchers for the purpose of creating new knowledge about real-world community issues in order to bring about change. CBPR has become increasingly important in healthcare provision as communities are being required to take greater ownership and control over decisions affecting the health of their people, especially in vulnerable communities (Hills & Mullett 2000).

CBPR actively seeks to empower a community affected by the issue being studied, and to make decisions affecting the people in their communities (Rhodes, Malow & Jolly 2010). This methodology was chosen because of its equitable, inclusive, collaborative, empowering, and systematic approach (Hills & Mullett, 2000). By providing meaningful and relevant evidence about real-world practices in the community, CBPR provided a balance between the contributions made to the discovery of new contextual knowledge by the research community and academic research. It generated a sustainable collaboration between the community and the digital healthcare researcher in the development and implementation of the research. CBPR facilitated the translation and transition of the research community's findings into improved quality healthcare provision at a local level, generating insights for the future development and implementation of MyHR.

#### ***3.3.1.1 Rationale for using a community based participatory research methodology***

The rationale for identifying a CBPR method as a suitable approach was that it would:

- support the research topic, which reflected concern of the community;

- increase the relevance and application of the research data by involving all partners;
- bring together partners with different skills, knowledge, and expertise to address complex problems;
- enhance the quality, validity, and practicality of research by involving the community knowledge of the partners;
- increase the likelihood of overcoming the distrust of research by communities traditionally the ‘subjects’ of such research;
- aim to engage communities in their health and well-being (Israel, B et al. 1998; O’Fallon, Tyson & Dearry 2000).

By using a CBPR approach we aimed to explore and increase knowledge and understanding of the contemporary healthcare provision requirements of people living with CCCs in rural community, and to integrate the knowledge gained with their experience of and engagement with MyHR, to inform and ultimately improve the health and quality of life of vulnerable community members.

The implementation of CBPR provided a guide for working with people in a community. It recognised the value of multiple ways of knowing and, more significantly, it recognised the value of the knowledge that the research community contributed to the co-creation of new knowledge. The use of an extended epistemology with CBPR broadened the response to the question ‘what constitutes evidence for community practice with people?’ (Hills & Mullett 2000, p. 9). The CBPR focus on real-world issues, problem solving, and change provided evidence for practice that was immediately useful and relevant to the research partners, the local community, and the wider communities, making a significant contribution to the requirements of MyHR and to debates about what constitutes evidence-based practice.

### ***3.3.1.2 The principles of community based participatory research***

CBPR is guided by the set of principles (Hills & Mullett 2000) outlined in Table 6, which also provides a research-specific description that explains how each of the principles was addressed.

**Table 6. Principles of community based participatory research**

Principles of CBPR	Description of research actions
CBPR is a systematic and planned process	The community's concerns were formalised into research questions and objectives. The research community's active involvement in a transparent and systematic development, implementation and evaluation process increased the likelihood that the findings will be both useful and translatable into changes in healthcare provision that benefit the community and wider community
CBPR is relevant to the community	The research provided information that was immediately useful and relevant to the community, who identified the topic. It explored their experience of and engagement with MyHR in order to observe, record and report the opportunities and weaknesses of MyHR, and ultimately to inform and improve access to contemporary digital healthcare provision for vulnerable communities
CBPR requires community involvement	The community identified the opportunity/topic, and the research community were actively involved in the research from its initiation. They understood that the research process required full involvement and a collaborative partner/researcher partnership. There was joint responsibility for decision making throughout, with an emphasis on the strength of the partners' contributions
CBPR has a problem solving focus	A real-world practical concern of the community was addressed; engaging people living with CCCs in a rural community to better understand and integrate their healthcare requirements, and ultimately to reduce health disparities. The research provided a solution to a problem and identified future requirements
CBPR focuses on societal change	The research as a collaborative process allowed the research community to develop new ways of thinking, behaving and practicing
CBPR is about sustainability	The research made a lasting contribution by introducing MyHR as an ongoing method of person-centred communication and collaboration for healthcare provision. It also empowered the research community with skills allowing for future research opportunities.

The principles of CBPR, firmly seated in the participatory paradigm, fulfil the humanistic requirements for research within the community in a real-world context. Adapting the principles of CBPR into a checklist ensured adherence to the philosophy and principles of CBPR. As presented in Table 7 and Appendix B, this directly illustrates how the rationale was achieved and supported the research community by providing a continual checklist to ensure that relevance, rigour, and validation was addressed.

**Table 7. Checklist for adherence to philosophy and principles of CBPR**

Principles of community based participatory research	
<b>Systematic and planned process</b>	How does your research plan systematically address the research question?
	What is the logical relationship between the research question, methodology and methods?
	How does the research process incorporate the multiple ways of knowing?
<b>Relevant to the community</b>	Who generated the research issue?
	How is this a community issue?
<b>Requires community</b>	What mechanisms are in place to include people in the planning,

<b>involvement</b>	management and dissemination of the research?
	Are all the stakeholders who need to be involved, involved?
	How will decisions be made about the research process?
<b>Problem-solving focus</b>	What is the community's practical problem or topic that is being addressed?
	How will researching this issue help the community?
<b>Focuses on Societal Change</b>	What changes are anticipated?
	How is the research process structured to allow for reflection and iteration?
	Who will implement the changes?
	How is theory generated from and for practice?
<b>Sustainability</b>	What will the community have at the end of the research?
	How does the research outcome enhance human flourishing?

The use of CBPR as a guide to data gathering and translation can significantly improve the relevance, rigour, and validation of data (Minkler 2014). It was considered appropriate to actively engage the research community in problem definition, design of interventions, data collection, and analysis. This ensured that traditionally data-driven practices were meaningful, valid, and relevant. It also helped to build the capacity of both the community and individuals to study and address health and social issues of concern to them. Because the research involved working with a vulnerable community during their experience of and engagement of MyHR, it was considered important that CBPR was used.

### 3.3.2 The community

The community, depicted in Figure 5, were two Tasmanian local government areas (LGAs), Central Highlands and Southern Midlands. Both LGAs hold a rural area (RA) classifications of RA 2/3 (outer regional/remote Australia) (ABS 2011). An RA classification is an indicator of remoteness, based on road distance to service centres and a measure of distance from other people. The community area involved in this research is classified RA2/3, because the population of the closest urban centre is less than 10,000.



**Figure 5. Tasmanian context of researched community**

The term ‘outer regional/remote’ encompasses all areas outside Australia’s major cities. Designed by the Australian Bureau of Statistics, the Australian Standard Geographical Classification System classifies areas as RA1: inner regional, RA2: outer regional, RA3: remote, or RA4: very remote (ABS 2011). The purpose of classifying areas is to divide Australia into broad geographic regions that share common characteristics of remoteness for statistical and research purposes (ABS 2011).

To provide better context for the research, the research community considered it appropriate to provide a brief health risk-factor profile and health outcomes of the adults living in the community. The DHHS (2013) provided the following summary information.

### ***3.3.1.1 Central Highlands Tasmania***

The risk factor profile and health outcomes of adults living in the Central Highlands compared to Tasmania as a whole demonstrate that:

- 21.8% of adults drink alcohol at short-term risky levels;
- 88.8% of adults eat inadequate daily amounts of fruit and vegetables;
- 47.8% of adults had been screened for high blood pressure in the past two years;
- 37.4% of adults had been screened for diabetes/high blood sugar levels in the past two years;
- the incidence rate of all-cause cancer is 571.7 per 100,000, the third highest of all Tasmanian LGAs.

### ***3.3.1.2 Southern Midlands Tasmania***

The risk factor profile and health outcomes of adults living in the Southern Midlands compared to the Tasmania as a whole demonstrate that:

- 29.7% of adults are daily smokers, the highest rate of all Tasmanian LGAs;
- 64.2% of adults eat inadequate daily amounts of fruit and vegetables;
- 86.8% of adults have been screened for high blood cholesterol in the past two years;
- 64.9% of adults had been screened for diabetes/high blood sugar levels in the past two years;
- the incidence rate of all-cause cancer is 619.6 per 100,000, the highest of all Tasmanian LGAs.

Limited access to quality healthcare provision restricts the engagement of this community and intensifies their vulnerability. Inclusion in healthcare provision and ongoing education are critical to engage and involve these people. This requires that they engage with routinely measurement and monitoring of symptoms, medications, and lifestyle changes, thereby remaining active partners in their healthcare provision and members of their community. The use of digital technology such as MyHR provides an opportunity to offer a continuum of quality healthcare provision and reduce disparities in care.

### 3.3.3 The research community

During an annual review of their community healthcare provision, people living with CCCs in rural southern Tasmania identified the research topic as reflecting a concern of their community: i.e., in what capacity might a SDHR be beneficial for a person living with CCCs in a rural community and what obstacles might be encountered during their experience and engagement? Rural Primary Health Services Tasmania invited people living with CCCs who resided in Central Highlands and Southern Midlands LGAs (Figure 5) to attend an introductory meeting in one of three rural venues. These are depicted in Figure 6.

Creating a partnership between the people living with CCCs and the researcher enabled the participatory research. To provide context, the research community is defined as:

- including all those actively involved in the research (the partners and the researcher);
- the collaborative effort connecting the partners, the three groups, and the researcher as a research community at all stages of the research process;
- although the level of partner, group and researcher involvement varied at each stage of the research, the whole research process remained a joint responsibility, requiring the research community to share decision-making throughout the process;
- the distinction between the researcher and the researched was minimal; however, rather than viewing the partners, groups and the researcher as making equal contributions in the sense that they did the same thing, the CBPR emphasised the unique expertise and contributions of each partner and group and the researcher;
- the trust-centred relationship required openness, time and effort to build, and recognised and valued the work and perspectives of all the research community;



- the understanding and cooperation maximised the contributions of each partner and group, which focused on their shared responsibility for the research and research processes.

Figure 6 shows a map indicating the location of the research group meeting venues and the partners' homes in the context of the community.



Figure 6. Research groups and partner location in context of community

### 3.3.4 The research partners

Terminology matters. There is a need to clarify the meanings of ‘people’, ‘person’, ‘partner’, and ‘patient’ and their relationships with healthcare provision, MyHR and CBPR. ‘People’ are a group or community of persons living with CCCs. A ‘person’ is an individual member who contributes to a group or community. Each person is defined by the attributes and functions they bring to the role (Sturmberg 2014). A group or community provides a sense of identity and an emotional connection to other people, shared values, and norms, common interests and a commitment to meeting shared needs (Israel, B et al. 1998).

The methodological approach used in this research provided guidance for a research community of people as partners. Other research approaches often refer to people as participants, patients, or consumers. This research uses the term ‘partner’ because the term ‘participants’ suggests a relatively passive role in a research activity, and the

term ‘patient’ presumes an illness and a decreased ability to make rational decisions, excusing the individual from responsibility for their incapacity. In research and healthcare provision, this terminology has been modified by changing people from ‘patients’ to ‘consumers’. This is widely perceived as politically correct, because it implies that people have consumers’ rights to select their healthcare provision (Showell 2011; Sturmberg 2014). However, to take this a step further, people should, rather than being considered as passive participants, patients, consumers, or objects of research (Bergold & Thomas 2012), be viewed as respected partners in the process of inquiry. They should be considered knowing participants capable of developing their own ideas and working together to see if their ideas make sense of their world, work in practice and provide a framework for validation (Heron & Reason 2001; Keaney 1999). Hence, this research uses the term ‘partner’ to refer to an individual member of a research community equitably involved in all aspects of the research who contributes expertise, shares decision-making and takes ownership.

### **3.3.5 The researcher**

A necessary factor for the success of the research was the researcher’s involvement in and commitment to ensuring that the topic, identified by the community, remained informative and of interest to the research community. A key component of the approach was that the researcher acted as a facilitator, and was known, trusted, and embedded in local community knowledge and opinions (Chenoweth & Kilstoff 1998; Hansen 2006b; Minkler 2004; Reason 1994). The researcher has worked as a healthcare professional across rural Tasmania and was previously known to some of the partners, but did not reside in the community. Other key components of being invited and engaged as a trusted researcher were considered to be:

- providing an introduction to the reason the research was being conducted and answering any questions from the community;
- complete openness and honesty;
- clear and natural explanations delivered as regular conversation;
- sincerity in outlining all the research issues that must be discussed;
- taking their work seriously;

- that their concern, above all, was for the comfort of the research community.

The researcher's role as a facilitator required their recognition of a personal requirement to adopt a reflexive role, by consciously thinking about issues such as building trust-centred relationships, respecting values and perspectives, and considering the ethical challenges of being an 'initiator' in the research process. The researcher recognised the paradox, acknowledging that the research would likely not occur without their 'initiation' and their commitment, time, skills, and knowledge. The researcher also recognised that 'initiator' was only one of their several roles in the research community. Other roles included organisation and facilitation of partner and group dynamics, essential for successfully building trust-centred relationships, and an increasing contribution to the discussion and guidance of the research community through the whole research process (Hansen 2006b; Minkler 2004; Reason 1994). The practical detail of how the researcher ensured they maintained a reflexive role for the duration of the research is discussed and demonstrated in section 3.5 Validation and rigour, and in Table 18.

Identifying with CBPR allowed the researcher to remain engaged with the research community and facilitate the research, and to acknowledge and value the effect and affect on the research of the partners' own backgrounds and experiences while exploring and recognising their social world through the partners' own perspectives (Mertens 2005; Ritchie & Lewis 2003). The researcher remained in a reflexive role, aware of 'what the researcher knows' and 'how the researcher came to know this' and the influence their beliefs and behaviours could have on the research process (Barry et al. 1999; Darawsheh 2014; Greenhalgh et al. 2015; Hansen 2006b; Ritchie et al. 2013).

To ensure full participation of all research partners, the research strategy required a contextual, practical, research design, involving a series of flexible, transparent phases of both data collection and data analysis, each of which progressed through iterations of planning, implementation, and evaluation. The research commenced with an introduction and recruitment stage. This was followed by three phases of data collection: pre-experience of MyHR, registration and early engagement with MyHR, and post-experience and engagement with MyHR; followed by three phases of thematic data analysis: data description, data management, and data explanation.

These stages are described in detail in the research design section 3.4.

### 3.4 RESEARCH DESIGN

This section presents the research design for collection and analysis of the data. It describes the recruitment of the partners, the introductory group meeting, data collection methods, data collection, and data analysis. The design aimed to ensure validation, rigour, and relevance of the research, combined with economy in procedures. The research design enabled the research to address the following research objectives (Ro) and questions (Rq):

**Ro1.** To clarify what people living with CCCs in a rural community require from MyHR.

**Ro2.** To recognise how people living with CCCs in a rural community experience MyHR.

**Ro3.** To investigate why people living with CCCs in a rural community engage with MyHR.

**Rq1.** What is the experience of MyHR for people living with CCCs in a rural community?

**Rq2.** Why do people living with CCCs in a rural community engage with MyHR?

The research design consisted of a series of practical and logical stages, which progressed through iterations of action and reflection: an introduction, three phases of data collection with concurrent data transcription and verification (member checking), and three phases of data analysis and discussion. Data collection techniques comprised group meetings, SSIs and the researcher's reflective journal. Data collection tools comprised audio recordings, group and SSI guides, and MyHR. Data analysis was guided by the use of a thematic framework approach.

Table 8 outlines the research process, phases of data collection, analysis techniques, and the tools used. These processes were displayed and discussed at the beginning and end of each group meeting. This ensured maintenance of ethical integrity, adherence to the principles of CBPR, and allowed group consensus and fully informed participation in the research process. The research community considered it

important that the processes remain transparent, flexible, and iterative, adapting to the needs and demands of the changing situation of all partners and MyHR.

**Table 8. Research process**

Process	Phase	Data collection/analysis techniques	Data collection/analysis tools
Introduction & recruitment			
Data Collection	One	3 local group meetings	Group guide
			Live demo of MyHR
			Audio recordings
			Reflective journal notes and memos
		19 semi-structured interviews	SSI guide
			Live demo of MyHR
			Audio recordings
			Reflective journal notes
	Two	19 semi-structured interviews	MyHR registration
			Audio recordings
			Reflective journal notes
		3 local group meetings	Group guide
			Live demo of MyHR
			Audio recordings
			Reflective journal notes and memos
Data Analysis	One	Data Management	Stage 1. Familiarisation
			Stage 2. Development of initial thematic framework
	Two	Date Description	Stage 3. Indexing and charting
			Stage 4. Mapping
	Three	Data Explanation	Stage 5. Interpretation

### 3.4.1 Recruitment of partners

The focus of the research was how people living with CCCs in a rural community experienced and engaged with MyHR. A purposeful sampling technique, widely used in qualitative research, was considered most suitable to identify traditionally marginalised vulnerable people as potential partners and to obtain rich examples of real-world experiences, thus gaining meaningful information while making the most effective use of limited resources (Barbour 2001; Patton 1990; Tongco 2007).

The technique enabled recruitment consistent with the research objectives described in section 1.2.2. The researcher minimised selection bias by asking Rural Primary Health Services, Tasmania (a community based organisation) to invite people living with CCCs in the LGAs of Central Highlands and Southern Midlands to introductory group meetings, keeping in mind the need to recruit a variety of people older than 18

years who were living with CCCs. The sampling technique focused on people purposefully selected to participate because of:

- their diverse and in-depth knowledge of the real-world issues of living with CCCs in rural communities;
- their immediate and future requirements for the delivery of quality healthcare provision;
- they identified that a SDHR may be extremely relevant to the needs of their current and future healthcare provision.

To facilitate interactions with this vulnerable population, the inclusion criteria (listed in Table 9) were as broad as possible to avoid excluding any people living with CCCs in the rural community. This group was chosen because they account for a significant proportion of people for whom a SDHR is likely to be essential for future quality healthcare provision (Campbell, M et al. 2000).

**Table 9. Inclusion and exclusion criteria**

Inclusion criteria	Exclusion criteria
Two or more CCCs	Under 18 years of age
Live in Tasmania's local government areas of Central Highlands of Southern Midlands	Mentally unable to understand consent and contribute to the research
	Unable to speak or understand the English language

### 3.4.2 Introductory group meetings

Prior to the introductory group meetings the research received full ethics approval by the social sciences Human Research Ethics Committee (H0013781) (Appendix C) and Rural Primary Health Services Tasmania agreement (Appendix D).

Rural Primary Health Services Tasmania:

- invited people living with CCCs to attend an introductory group meeting in one of three rural locations outlined in Figure 6;
- selected the most appropriate location for the group meetings to maximise the impact of the investigation in the time period available and to minimise the impact of data collection on the potential partners (Teufel-Shone & Williams 2010);
- convened the three introductory group meetings.

The researcher focused on facilitating research issues confronting people living with CCCs, and the concept of the MyHR as a digital resource for recording their CCCs as personal health notes or summaries.

The introductory group meetings were designed to be interactive and to guide open discussion regarding the research methodology and the concept of MyHR. Planning and decision-making were critical to maintaining the CBPR principles. The sessions:

- enabled a focus on the importance of the research methodology and the engagement and involvement of the partners and researcher as a research community in all aspects of the research process, with the outcome of increased combined knowledge and the achievement of improved health and wellbeing for the community;
- introduced the concept of MyHR as a SDHR, a digital documentation and communication resource;
- ensured that approaches were agreed upon and facilitated a discussion about inclusion and exclusion criteria and the commitment required to ensure successful completion of the research;
- formalised the research process, so that those people who wished to participate and met the inclusion criteria (section 3.4.1 Table 9) proceeded to become research partners.

Because the three introductory group meetings were intended to communicate preliminary research information and the research process, no consent to take part was required. For ethical reasons no research data were recorded at these meetings. At the conclusion of the introductory group meetings, all attendees, 23 in total, were provided with further verbal and written research information (Appendix E) and consent forms (Appendix F), to be completed if the attendee wished to become a research partner.

Of the 23 attendees, 19 people met the inclusion criteria and wished to become involved in the research. The reasons that four attendees withdrew were: two because they felt that the current healthcare provision they received was adequate, one because they lived outside the community (accompanied a friend on the day), and one because they denied the diagnosis of two or more CCCs. Therefore, 19 people with a diagnosis of two or more CCCs residing in the rural LGAs of Central

Highlands or the Southern Midlands of Tasmania continued to become partners in the research community.

These 19 people were re-read the research information sheet (Appendix E) and consent form (Appendix F). Once the consent forms were signed, dated and returned to the researcher, to be securely stored for future reference if required, the 19 people were considered partners in a research community.

### **3.4.3 Data collection methods**

Data collection was conducted over a 12-month period, from February 2014 to February 2015. The research community agreed to:

- the data collection techniques: group meetings, SSIs and the researcher's reflective journal;
- the data collection tools: audio recordings, a group guide (Appendix G), an SSI guide (Appendix H), and live interaction with MyHR as a healthcare user.

To validate the research and to maintain ethical integrity, verbal consent and the adherence checklist adapted from (Hills & Mullett 2000) were reaffirmed on each occasion of data collection. The adherence checklist ensured partner and group consensus, fully informed participation, and adherence to the principles of CBPR. It has been previously discussed and described in section 3.3.1.2 and is available as Appendix B.

#### ***3.4.3.1 Data collection techniques***

The research used group meetings, SSIs and the researcher's reflective journal as data collection techniques. Group meetings and SSIs were chosen as appropriate techniques to understand the strengths or weakness of the research community that could engage or delay experience of and engagement with MyHR. They provided opportunities for investigation within and between the groups and the partners, which encouraged the research community to probe particular topics further as they came up in discussions. The researcher's reflective journal provided a resource to record memos, notes, and what the researcher saw, heard, and felt outside the context of the process. The details of each technique are described below.



### *Group meetings*

One group meeting was facilitated in each location (Figure 6) during each phase of data collection, as indicated in Table 8, Section 3.4. The three group venues arranged by Rural Primary Health Services, Tasmania for the introductory meetings remained the venues for the group meetings throughout the data collection period. This was because the partners agreed that the local venues facilitated attendance with minimum disruption for the partners, who each lived within 10 kilometres of their chosen group venue. The research rationale for using group meetings was that they are widely used in qualitative research as an effective technique to explore people's attitudes, needs and experiences of disease and digital health provision (Ayala & Elder 2011; Bristowe, Selman & Murtagh 2015; Kitzinger 1995).

The group meetings explored the experience of and engagement with MyHR from the perspective of people living with CCCs in a rural community. Using group meetings generated data by collecting the partners as a group to allow interaction, collaboration, and communication, and allowing them to explore and explain their views in ways that may not have been retrieved in the one-to-one SSIs. The group meetings were not intended to be, or used as, a replacement for the SSIs; the two processes were used in combination. The meetings were convened with the intention of introducing and exploring subjects further and possibly in different directions than achieved in the interviews (Bristowe, Selman & Murtagh 2015; Kitzinger 1995; Sturmberg 2014).

Group meeting attendance varied from two to 10. The groups were made up of representative partners; not all partners could attend all group meetings. The researcher, as facilitator, ensured that the more vocal partners did not dominate the groups. Group homogeneity provided a comfortable environment for the partners. Creating three separate homogenous groups, all living within one rural community, allowed for comparison of group views that may have influenced the partners' experience of and engagement with MyHR. Any heterogeneity within and between the groups could also provide evidence of important group differences to be considered within the context of the community (Ayala & Elder 2011; Bristowe, Selman & Murtagh 2015; Kitzinger 1995).

Data were collected from three group meetings held during each phase. Each group met for 90–120 minutes, depending on the group size, the number of questions asked and how talkative the group was. The potential group ‘pros’ and ‘cons’ are described and the research actions taken are highlighted in Table 10 adapted from Sweeny, Pritchard and Yao (2010).

**Table 10. Pros and cons of group meetings**

Pros	Cons	Research application
Provided valuable information to explore and clarify the research objectives	Research takes place in an unnatural setting	The group settings and refreshments were identified and arranged by the Rural Primary Health Services Tasmania for their locality, comfort, ease of access and privacy
Provided valuable information in the context of partners’ experiences of taking part in research	Can stray from desired topic because of group discussion process	The researcher used the skills of sensitivity and awareness. The group guide and principles of CBPR ensured that groups maintained research significance and the discussions remained context aware.
Avoided discrimination against partners who may not be able to read or write	Can be hard to replicate	It is expected that the research will be transferable. The research topic, methodology and design were chosen to identify real-world benefits and obstacles confronted for MyHR, CCCs, rural Australia
Encouraged participation; from those who may be reluctant to be interviewed on their own	Impersonal, group discussions do not lend themselves to personal revelations	The research was designed so that the research community was encouraged to assist in deciding appropriate data collection techniques and tools. The data collection techniques also included one-to-one interviews. For those partners who may have felt uncomfortable sharing all their opinions or experiences in a group setting, individual interviews allowed for expression and expansion on group experiences. A means of obtaining further information.
Encouraged contribution from individuals who feel they have nothing to say	Difficult to control	The researcher as a facilitator kept the discussion on track. However, for the groups to be informative, the conversation must flow naturally to reveal what the partners were thinking.
Gathered data in relation to the partners’ perceptions and attitudes about their MyHR	Dominating individuals	The researcher as a facilitator ensured that group discussions involved everyone, all the partners had equal time and that all points of view were valued and heard. The goal of the group discussions was to discover what all the partners thought.
Supported a group approach to decision making and subsequent action	Unrepresentative	The partners’ interviews and group discussions were unlikely to be representative of the larger population. It was never assumed that the opinions uncovered would have any significance other than the insights they offered into possible thought patterns. The qualitative research topic, methodology and design were chosen to identify benefits and obstacles in using MyHR encountered by people with CCCs in rural Australia. It was expected that the discussion would generate evidence supporting the future implementation of MyHR in vulnerable communities and provide targeted questions for future research.
Encouraged trust and rapport between group members		A key component of the methodological approach was that the researcher was known, well-trusted and embedded in local knowledge and opinions. The CBPR approach and purposeful sampling recruitment assisted the

		process. Trust-centred relationships further developed throughout the research, evidenced in the data interpretation, findings and discussion.
Explored and clarified views in ways that may be less accessible in a one-to-one interview	One-to-one interviews can be intimidating	The research was designed to encourage the research community to assist in deciding appropriate data collection techniques and tools. The data collection tools included groups for those partners who may have felt uncomfortable sharing all their opinions or experiences in a one-to-one environment. Groups also allowed for expression and expansion on individual experiences. A means of obtaining further information.

### *Semi-structured interviews*

SSIs were facilitated in each phase of data collection, as shown in Table 8. Section 3.4. The research rationale for using SSIs was to identify commonality and variation in the partners' personal experiences of and engagement with MyHR and in that reported at the group meetings. The interview experiences provided the partners with further interconnection and an opportunity to share their stories when they met at group meetings.

The appropriate choice of interview structure depends on the research philosophy, research question, aims and objectives (Ritchie et al. 2013). The three major categories of interviews used are standardised/formal/structured, un-standardised/informal/unstructured and semi-standardised/focused/semi-structured. This research used SSIs because of an understanding that the use of structured interviews would preclude the ability to probe further on issues related to the partners' experience of and engagement with MyHR. Equally, the use of an unstructured interview may have given the partner too little guidance when responding to questions, leading both parties to digress during the interview. Using SSIs incorporated both options and provided an interview structure (Cottrell & McKenzie 2010).

Data were collected from 19 SSIs held during each phase. Each interview lasted between 60 and 90 minutes, depending on the response to the questions asked, how talkative the partner was, and interruptions. The SSIs were conducted as one-to-one conversations between the partners and the researcher, at a time and location where the partners were most likely to access and interact with MyHR; the partners could request to meet at either their home, an online centre or a day centre. The location ensured that the partner felt comfortable to speak freely, encouraged ownership and

provided the researcher with an ideal opportunity to assess the partner's contextual experience of and engagement with MyHR. Conducting SSIs where behaviours naturally occur may also improve transferability and the opportunity to address contextually relevant stimuli, e.g., family, access to computer, and internet connectivity, to inform their experience of and engagement with MyHR.

Other considerations in deciding to conduct the SSIs in combination with group meetings were to ensure that each partner had a voice. Asking partners to come to a central location may have biased the sample to people able to travel independently and who had both the time and motivation to participate and the necessary transportation and childcare.

Further potential SSI 'pros' and 'cons' are described and research actions taken are highlighted in Table 11, adapted from Sweeny, Pritchard and Yao (2010).

**Table 11. Pros and cons of semi-structured interviews**

Pros	Cons	Research application
Provides valuable personal information within the context of partner experience	May be considered too expensive, time consuming or inconvenient to collect and analyse data	Semi-structured interviews were considered necessary for the collection of personally and contextually relevant data for discussion and comparison with group data
The use of predetermined questions provides uniformity	Requires some knowledge in order to prevent interviewer suggesting answers	The researcher considered the following qualities necessary: <i>Practice</i> - prepare for the interview <i>Small talk and dress</i> - develop a rapport with the partner <i>Be natural</i> - inform the partner about the reasons for the questions <i>Listen</i> - record the answers <i>Keep goals in mind</i> - ask questions that require detailed answers <i>Respect</i> <i>Know when to end the interview</i>

### *Researcher's reflective journal*

During each phase of data collection, the researcher recorded group memos and notes in a reflective journal following group meetings and interviews, as shown in Table 8. Section 3.4. The reflective journal provided a conventional, hand-written method of additional data collection. During and immediately following the group meetings and interviews, the reflective journal provided the researcher with a resource to record meeting memos and notes, and what the researcher saw, heard and felt beyond the context of the meeting. The research rationale for keeping a reflective journal was to record an extremely positive or negative response to a question or

topic to later inform the data analysis (Bristowe, Selman & Murtagh 2015; Ritchie et al. 2013).

During the group meetings, the researcher wrote memos in the reflective journal. These assisted in collating information from the group discussions and provided continuity and context for consideration at each subsequent meeting. This also made certain that the memos were an accurate representation of the group processes, ensured accountability, and that all the research objectives were considered. The memos provided a cumulative reference to the topics and key issues raised in the groups, which assisted the iterative analysis and the process of moving data to a conceptual level (Appendix G). Notes written immediately after the group meetings were used as a reflection of the group organisation, dynamics and the responses to questions.

The researcher also wrote notes in the reflective journal immediately after the interviews. These provided a journal of the interactions, organisation, partner and researcher dynamics and the responses to any questions. The notes were summarised and used as a guide at subsequent interviews, again making certain of accurate representation of the processes, ensuring accountability, and that all the research objectives were considered.

After each encounter had been transcribed and confirmed by the groups or partners, the researcher's reflective notes were compared with the group and interview data to identify similarities and differences between the researcher's observations of the processes and the audio-recorded information. Potential reflective journal 'pros' and 'cons' are described and research actions taken are highlighted in Table 12, adapted from Sweeny, Pritchard and Yao (2010).

**Table 12. Pros and cons of researcher's reflective journal**

Pros	Cons	Research application
Provides an insight into what works and what does not	Requires research staff or participants to be diligent about keeping the journal up to date	The researcher used the reflective journal to keep group meeting memos to be used and agreed at subsequent meetings. In this way, keeping a reflective journal after each research contact became a part of routine data collection
Provides valuable information into the process of change	The values of the journal writers may influence their recording of events	To ensure that the process remained rigorous the researcher adopted a reflexive approach. This is discussed in section 3.5
	Not always easy to analyse	The researcher's reflective journal notes and memos were compared with the group data and interview data to identify similarities and differences between the researcher's observations of processes and the

		audio-recorded information.
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### ***3.4.3.2 Data collection tools***

The data collection tools comprised audio-recorded data, group meeting guides (Appendix G), SSI guides (Appendix H), and live experiences of MyHR as a healthcare user. The data collection tools assisted group meetings and SSIs in a number of ways: by stimulating discussions, clarifying decision-making about all aspects of the research process, identifying the need for support, and reflecting on the researcher's perceptions of group processes and interpersonal relationships. To avoid a research bias, plain English was used in the meeting and interview guides to minimise the need to adjust the wording of questions to fit the partners.

#### *Group meeting data collection tools*

Group meeting data collection tools comprised audio recordings, a group meeting guide and live experience of MyHR as a healthcare user. The group meeting guide (Appendix G) was developed, agreed and used to ensure that all the group meetings remained focused. The researcher used the guide as a meeting outline to support comfortable group interactions and to ensure that the research objectives were addressed. The researcher openly asked questions while observing and considering the dynamics of the groups.

To establish rapport, a general non-threatening introduction to the groups and the topics was followed by a short interactive PowerPoint presentation and live experience of MyHR. Refreshments and further discussion concluded each group meeting. The purpose of the brief introduction and refreshments was to assist the partners in each group to feel comfortable speaking freely and to encourage ownership. Krueger and Casey (2000) support this approach because it allows the researcher to investigate responses to general questions with a specific focus related to the research objectives. Questions about more specific and potentially controversial topics usually followed the PowerPoint presentations and live experience of MyHR.

The researcher facilitated a blend of general and specific, open and closed questions, to obtain key information about the acceptability of the research (Kitzinger 1995; Krueger & Casey 2000). Open general questions were used at the start of the group meetings to get the partners to begin thinking about the topic; e.g., 'What do you

think about your research idea and the design?’ Specific open questions were used to gather information about particular behaviours or attitudes following the presentations; e.g., ‘How do you think you can use the digital health record (MyHR)?’. Closed questions, whether specific or general, were used at the close of the group meetings; e.g., when interview and future group meetings dates and times were discussed. The researcher guided the conclusion of each group meeting by asking the partners whether ‘anything was left out of our discussion’, to elicit any remaining important elements related to the topics of interest. To ensure that the principles of CBPR were being adhered to, the checklist (Appendix B) was reaffirmed.

During each group meeting, a presentation and live access to MyHR provided an opportunity to share, learn, identify support, consolidate and question their experiences of and engagement with MyHR. The audio-recorded data provided an essential source of contextually significant evidence to address the research questions.

#### *Semi-structured interview data collection tools*

Data collection tools used in the SSIs comprised audio recordings, a SSI guide and live experience of or engagement with MyHR as a healthcare user. The success of the SSI depended on the skill and sensitivity of the researcher, particularly when exploring thought-provoking subjects. The SSI guide (Appendix F) and live experience of and engagement with MyHR provided a focus for the interviews and ensured that all the research objectives were considered consistently. The researcher involved each partner by asking a range of questions; e.g., closed general demographic questions and open-ended specific questions about their experience of and engagement with MyHR.

The interviews were conducted face-to-face and by telephone. The researcher considered face-to-face interviews the ideal in terms of developing trust, an in-depth understanding with each partner and allowing for easy clarification of questions (Ayala & Elder 2011; Ritchie et al. 2013). However, the researcher also recognised face-to-face interviews to be more costly in terms of time spent on data collection and travel time costs between each partner.

Telephone interviews were required for two partners during phase three, the post-experience of and engagement with MyHR interviews. These partners had moved significantly outside the geographical research area during the data collection period, making it impractical to conduct face-to-face interviews. However, both partners had contacted the researcher prior to their removal to express a wish to remain as partners in the research process. This was recognised and valued by the researcher as trust. The same interview guide (Appendix F) was used to guide the telephone interviews; both partners had access to MyHR. These telephone interviews were considered necessary because they allowed for complete collection of data.

During the SSIs, both face-to-face and telephone, live interaction with MyHR as a healthcare user provided focus and opportunity to question and develop a personal experience of MyHR. Once registration had been accomplished, the partners demonstrated their engagement with MyHR. This observed and audio-recorded information provided a further source of rich data to compare with the data from group meetings in addressing the research objectives and research questions.

#### *MyHR registration and early engagement data collection tools*

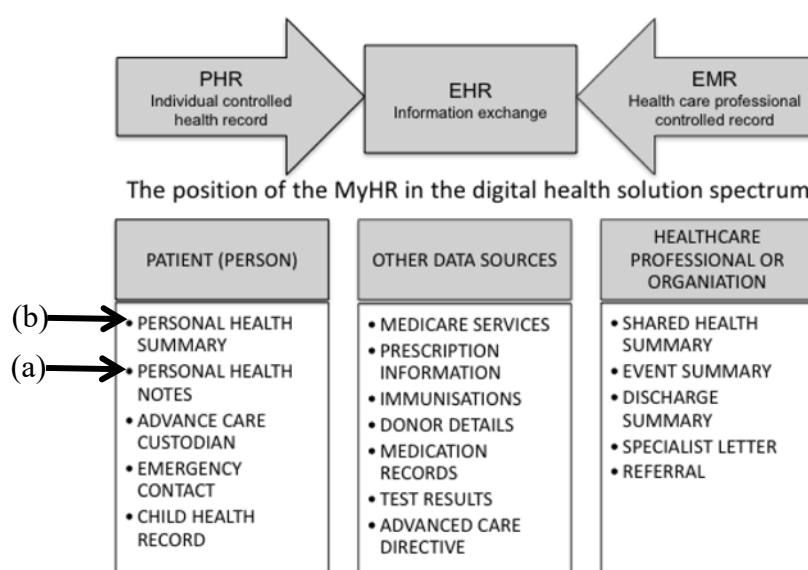
The tools for data collection about MyHR registration and early engagement comprised audio recordings and the researcher's reflective journal notes. During phase two, the researcher assisted and observed each partner individually through their complete MyHR registration process, using a personal or laptop computer. Where physical incapacity of a partner was identified, these partners chose to pair with another research partner who provided support. MyHR was accessible for engagement to all partners from phase two onwards.

All 19 partners completed MyHR registration during phase two; each partner demonstrated their experiences of and early engagement with MyHR. The personal health notes section within MyHR provided a digital health journal for partners to record their CCCs as personal experiences. This observed and audio-recorded information provided a further source of rich data to compare with the data from group meetings and from phase one and three interviews to address the research objectives and research questions.

As discussed in section 2.5.2, the structure of MyHR traverses those of a PHR (owned, managed and shared by the healthcare user), EHR and an EMR (healthcare



provider health records). Figure 7 identifies the position of personal health notes and the personal health summary within MyHR. The personal health record (PHR) provides those who have registered for MyHR with their own portal to record freely any Personal Health Notes (Figure 8 (a)) as one longitudinal record or as separate note entries. Personal Health Notes are not visible to, or accessible by, any healthcare provider. The Personal Health Summary (Figure 8 (b)) stores personal additions of key information, e.g., allergies, adverse reactions, and current prescription and over-the-counter medications. The Personal Health Summary, advanced care custodian, emergency contact, and child health record entries are accessible and visible to the healthcare users identified healthcare providers.



**Figure 7. Position of personal health notes and personal health summary within MyHR**

### 3.4.4 Data collection

The research partners, 19 people with a diagnosis of two or more CCCs who resided in the rural LGAs of Central Highlands or the Southern Midlands of Tasmania, provided data for collection during three phases.

#### 3.4.4.1 Data collection phase 1: pre-experience of MyHR

Phase one collected pre-experience of MyHR data. Data collection was achieved in three ways:

- three group meetings;
- 19 individual SSIs;

- the researcher's reflective journal.

Once consent was verbally established on the audio records of the group meetings and SSIs, adherence to the principles of CBPR was reiterated and addressed, and a live demonstration of a healthcare user MyHR portal was made available for observation. The researcher's reflective journal provided a further resource for data collection from the group meetings (in the form of memos and notes for reflection) and SSIs (in the form of notes for reflection). A critical aspect of the phase one group meetings and SSIs was building trust and rapport between the partners, groups and researcher.

Phase one group meetings continued research planning and decision making, which had commenced at the introductory meetings. They also identified potential concerns confronting the community regarding experience of and engagement with MyHR. This was achieved in two ways:

- adherence to CBPR principles to guide group discussions, identify achievements and reflect on the research processes. The groups voiced concerns and sought clarification of any relevant details required for them to remain fully involved in the research;
- live demonstration of a healthcare user MyHR portal focused the group discussions. This reinforced the commitment required by all partners when experiencing and engaging with MyHR. Once the groups agreed to the way that their MyHR was to be put into operation, the research progressed.

Data collection from SSIs identified for each partner:

- their demographic healthcare and medical profile;
- their personal ICT awareness and use;
- their understanding of and the potential obstacles confronting them regarding their experience of and engagement with MyHR;
- the feasibility of MyHR as a documentation and support resource for their CCCs and personal health notes.

#### ***3.4.4.2 Data collection phase 2: registration and early engagement with MyHR***

Phase 2 collected the partners' experience of and early engagement with MyHR data. This was achieved in three ways:

- 19 SSIs, which facilitated 19 assisted MyHR registrations and early engagement;
- three group meetings at which discussions included preliminary thoughts about personal and contextual experiences of and engagement with MyHR;
- the researcher's reflective journal.

Once consent to audio record the group meetings and SSIs (including assisted MyHR registrations) was verbally established, and the CBPR principles of the research were addressed, continued support for the experience and early engagement with MyHR was provided by memos from the previous group meetings and live access to a healthcare user MyHR. The researcher's reflective journal provided a further resource of data collection for MyHR registrations, experience and early engagement and group meetings. It was important that trust and rapport between all partners, groups and the researcher continued to develop during phase 2.

In phase 2, data collection about registration and early engagement with MyHR was achieved by gathering the partners' experience of:

- assisted MyHR registrations;
- early engagement with MyHR: entering emergency contact details and some CCCs and personal health experiences, into their Personal Health Notes or Personal Health Summary section within MyHR;
- the researcher's observation and reflection on the support needs of the groups.

Phase two group meetings followed the partners' registration and experience of and early engagement with MyHR. The data collection gathered:

- reflection and discussion about personally and contextually significant registration experience of and early engagement with MyHR;

- concerns voiced and clarification to be sought regarding the research process;
- the researcher's observation and reflection on the support needs of the groups.

#### ***3.4.4.3 Data collection phase 3: Post-experience of and engagement with MyHR***

Phase 3 data collection covered the post-experience of and engagement with MyHR. This was achieved in three ways:

- 19 SSIs facilitated the collection of personal and contextual experience of and engagement with MyHR and the usefulness of CBPR in a rural community;
- three group meetings facilitated contextually significant experience of and engagement with MyHR and the usefulness of CBPR in a rural community;
- the researcher's reflective journal.

Once consent to audio record the SSIs and group meetings was established verbally, the CBPR principles of the research were once again addressed. Memos from the previous group meetings and live access as a healthcare user to MyHR provided continued support in the experience of and engagement with MyHR. The researcher's reflective journal continued to provide a resource for data collection for the group meetings and SSIs. A critical aspect of phase 3 group meetings and SSIs was the now well-established trust-centred relationship within the research community.

The SSIs had two purposes. These were:

- to guide the partners toward reflection and discussion about their experience of and engagement with MyHR, and to ascertain personal perceptions of the value of MyHR as documentation and communication resource;
- to determine the usefulness of CBPR as a digital health educational and communication resource within the rural community.

The group meetings facilitated:

- information sharing to ascertain group perceptions of the value of MyHR as documentation and communication resource; live access to a healthcare user MyHR supported the interactive discussions;
- discussion of the usefulness of CBPR for the community.

### **3.4.5 Data analysis**

Data analysis was achieved in three phases, which began with the collection of raw data and continued through to interpretation of data. The research required a systematic, rigorous approach to data analysis that provided flexibility, transparency and allowed iterative movement between the raw data, emergent ideas, concepts and patterns (Hansen 2006a; Ritchie 1999; Srivastava & Hopwood 2009).

A thematic framework approach provided the conceptual structure, offering opportunity:

- for an overview to make sense and maximise the potential;
- demonstrate different analytical skills;
- data reflection;
- display order within and between partner, group and theme, whilst remaining faithful to the original data.

#### ***3.4.5.1 A Thematic Framework Approach***

It is important to use qualitative research as a means of exploring digital health related issues to understand the contextual perspective of the community issues and their needs (Sweeny, Pritchard & Yao 2010). However, qualitative research studies can present challenges, because they generate large volumes of narrative data to be analysed. Using a thematic framework approach recognises the requirement for a transparent, systematic, and rigorous method for management and analysis of the large amount of qualitative data collected.

Since its development in the late 1980s by Jane Ritchie and Liz Spencer (Ayres, Kavanaugh & Knafl 2003; DeSantis & Ugarriza 2000), the thematic framework approach has been used as a method for management, description and explanation of

qualitative data, for systematically collected narratives. It is now widely used in health research and more recently in digital health research (Ritchie & Lewis 2003).

A thematic framework approach was chosen for this research because of its data analysis process. It provides a flexible, reflexive tool, adaptable for use with many qualitative methodologies, which has the aim of generating themes. It is not aligned with any particular philosophical, epistemological, or theoretical approach (Smith & Firth 2011). A thematic framework, as an analytical approach, maintains that a social world exists independent of individual understanding and is accessible in qualitative research via the understandings of partners, which are further interpreted by the researcher (Gale et al. 2013; Ritchie & Lewis 2003; Ward et al. 2013).

Through a process of summarisation, the thematic framework approach allows for in-depth management, organisation, and exploration of the data, resulting in a flexible but rigorous output. The process used in this research involved three phases: data management, data description, and data explanation. This was achieved in five discrete stages: familiarisation, identifying a thematic framework, indexing, charting and mapping, and interpretation. All phases and stages interconnected to form a methodological and rigorous thematic framework. Although the stages can be undertaken in a linear fashion where all data are collected before analysis begins, this research used a non-linear, iterative strategy where data collection and analysis were concurrent. The thematic framework approach effectively provided a transparent, flexible, and systematic audit trail that enhanced the rigour of the analytical processes and the validity of the findings (Gale & Sultan 2013; Pope, Ziebland & Mays 2000; Swallow et al. 2014).

The rationale for adopting the concept of a thematic framework approach was that it provided a straightforward, comprehensive review of the partners' and groups' narratives, their original accounts and their reflections. The findings, interpretation and discussion can be clearly identified and related back to the original data (Gale et al. 2013; Lacey & Luff 2009; Leal et al. 2015; Ritchie & Lewis 2003; Smith & Firth 2011; Swallow, Newton & Van Lottum 2003; Ward et al. 2013). The thematic data analysis aimed to accurately and innovatively organise the data, identify repetitions and extract themes from the data while ensuring:

- a flow and sense between the data presented and research objectives;

- a clear and credible story line;
- interest and information;
- explanation of how and why the conclusions were reached (Berkowitz 1997).

The use of iteration in the data analysis also facilitated the researcher's reflexive process, taking into account the effect of the personality and presence of the researcher in the research community (Hansen 2006a). This was regarded as essential for producing insight and developing meaning. Reflexive iteration, or visiting and revisiting the data and connecting them, was crucial to sparking insight, developing meaning, and emerging insights, which then progressively led to a refined focus and understanding (Berkowitz 1997). The research community's experiences of and engagement with MyHR were captured, indexed as labels, charted to categories and finally mapped to themes. Once identified, the themes were interrogated as individual entities, and then the interrelationships were explained to ensure complete analysis. Using a thematic framework approach to analyse the data allowed innovation in its implementation while demonstrating logic (Berg 2004; Patton 2002; Srivastava & Hopwood 2009).

Using a thematic framework approach provided the data analysis with structure and established a rigorous process for managing data. Its flexibility allowed for creativity and assisted with adherence to the principles of CBPR (Houghton et al. 2015). Table 13, adapted from Houghton et al. (2015), displays the similarities between different data analysis approaches to qualitative research. However, unlike entirely inductive and interpretive approaches such as grounded theory, a thematic framework approach can be shaped by existing, *a priori* ideas and is less focused on producing a new theory (Ward et al. 2013).

**Table 13. Stages of data analysis**

Stages of thematic data analysis					
	Approach to data analysis (Houghton et al. 2015)	Stages of analysis (Lincoln & Guba 1985)	Analysis strategies (Morse 1994)	The framework approach to data analysis (Miles & Huberman 1994)	Purpose
1	Unitising	Comprehending	Broad coding	Familiarisation	Absorption in raw data, listing key ideas and recurrent themes <i>What are the research community saying that is relevant to the question?</i>

2	Categorising	Synthesising	Pattern coding Memo coding	Identifying and constructing and initial thematic framework	Refining the list to create meaningful analysis. <i>Under what headings can the research community experiences and engagement be organised?</i>
3	Filling in the patterns	Theorising	Distilling and ordering	Indexing and sorting	Annotation and labelling of data. Bringing together pieces of data into a recognisable group of concepts. <i>What parts of the data are about the same thing and belong together?</i>
4	Member checks	Re-contextualising	Developing propositions	Reviewing data extracts	Formalising the synthesis into a coherent set of explanations. <i>What other ways of organising the data are possible?</i>
5				Data summary and display	Generating a written précis for each theme and what each person is saying in the research <i>What in essence is the research community saying about each theme</i>

The research used a thematic framework approach for the data analysis because it could be shaped by *a priori* ideas: the research objectives, design, group (Appendix G) and interview guides (Appendix H), and emergent questions and topics. From initial management through to explanatory accounts the iterative, interconnected stages:

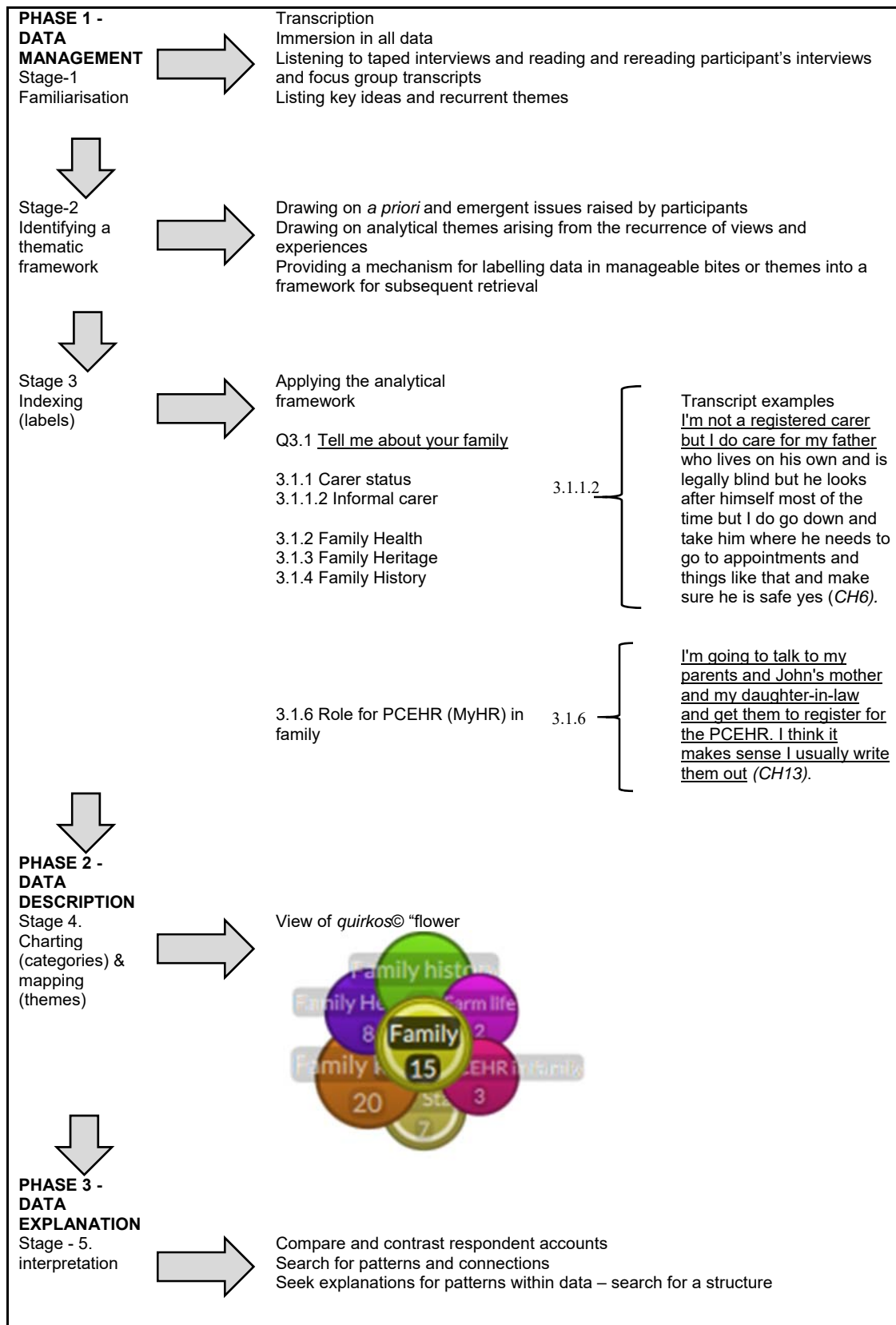
- provided descriptions and processes that guided the transparent analysis;
- provided a framework for a rigorous comprehensive investigation that strengthened and validated systematic data analysis and understanding;
- provided analysis driven by the research community's original accounts and thoughts;
- allowed for a complete review of the collected data.

#### *Phases and stages of data analysis*

The thematic framework approach used for the data analysis, depicted in Figure 8, has been adapted from Swallow, Newton and Van Lottum (2003), and as previously mentioned, although they are depicted as linear, interconnected phases, in practice the data management, description, and explanation were iterative. The analysis



systematically approached the phases of data management, description, and explanation in five iterative stages: familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation (Spencer, Ritchie, Ormston, et al. 2014). This is described in the following sections.



**Figure 8. Stages of thematic framework analysis application**

### ***3.4.5.2 Phase 1. Data management***

#### *Stage 1. Familiarisation*

The purpose of familiarisation was for the researcher to immerse themselves in the data, garner an overview of the substantive content, and identify topics and subjects of interest. Data analysis began during the data collection; the audio-recorded group meetings and interviews were transcribed verbatim to minimise important omissions (Ward et al. 2013). The transcribed data were then compared with the reflective journal memos and notes to identify similarities and differences between the researcher's observations of processes and the audio-recorded information.

#### *Transcription*

Transcription of the whole data set was the responsibility of and performed solely by the researcher. This ensured that there was no ambiguity in transcription style or formatting and reduced the time taken to become fully familiar with the data. The data were transcribed into individual word processor documents within one week of being audio-recorded. The group meeting data was aggregated per group to include understandings not limited to one partner. To avoid the potential for biased interpretations the partners approved their interview transcripts and the groups approved their group transcripts, comparing the researcher's account with those of the partner or the group.

#### *Immersion in the data*

Once all partners and groups had approved the transcripts, the researcher became immersed in the detail of each transcript. The researcher read and re-read each transcript, where necessary listening again to the audio recording and marking initial thoughts. This assisted in gaining a sense of the whole interview before indexing and labelling began. The process continued until the diversity within the data was understood (Rabiee 2004).

Srivastava and Hopwood (2009) state that where large volumes of qualitative research data are collected, not every piece of material may be reviewed during familiarisation. However, although the process was time consuming, the researcher considered that the research sample size allowed for all transcripts to be included at this stage. This was considered necessary for a complete process that ensured all data from each group and each partner were considered, and that data not commonly

repeated were not overlooked. This resulted in full inclusion and understanding of the data (Ward et al. 2013). Through continually organising and reviewing ideas in the context of the research objectives, questions, and guides, the researcher had, by the end of stage one, noted recurrent and non-recurrent ideas present in the data.

### *Stage 2 Identifying a thematic framework*

Having developed a list of possible topics for inclusion during Stage 1, the purpose of Stage 2 was to identify an initial thematic framework and commence organising the data by identifying headings and subheadings, leading toward the creation of meaningful analysis.

### *Developing an initial framework*

The large amount of data was managed by creating an initial framework. This was developed *a priori* from the research objectives, design, group (Appendix G) and interview guides (Appendix H), and emergent questions and topics. The initial framework comprised a list of possible topics that was sorted into a set of headings and subheadings. It was not considered permanent; it could be altered and refined at any time. An example of the initial framework is provided in Table 14; the complete initial analytical framework is presented in Appendix I.

**Table 14. Example of initial thematic framework**

<b>Data collection phase one pre-experience of and engagement with MyHR</b>		
Ro1. To clarify what people living with complex chronic conditions in a rural community require from MyHR		
Q3 Partner personal journey		
Q3.1 Tell me about your family	Q3.2 Tell me about yourself	Q3.3 Who is involved in your healthcare provision?
	Q3.2.1 Tell me about your health	<u>Emergent questions and topics</u> <u>Health practitioners?</u> <u>Health goals?</u>

### *Stage 3 Indexing to labels and charting to categories*

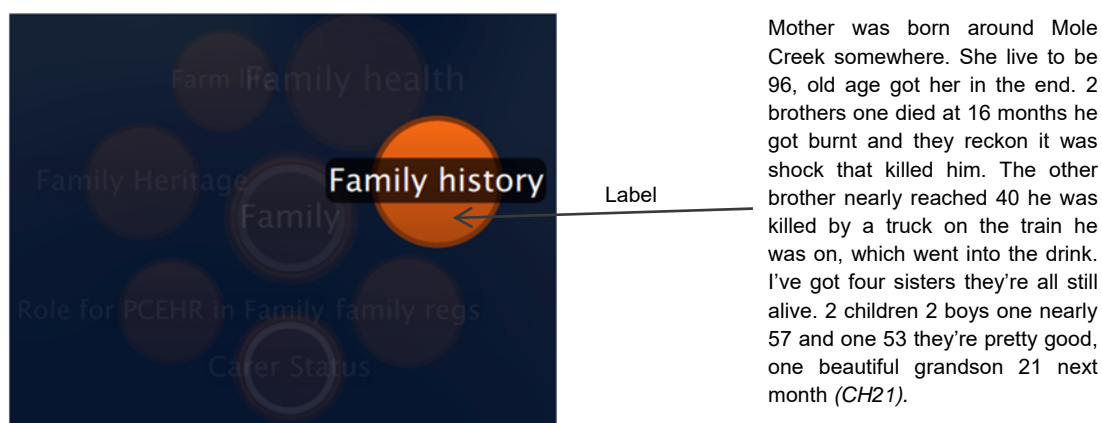
The purpose of Stage 3 was to bring order, understanding and meaning to the words, phrases, or paragraphs of the research community. This required indexing data to labels; the data was scrutinised, highlighted, and sorted; words, phrases, or paragraphs were compared within and between partners and groups.

From a practical perspective, handling the large amounts of transcribed data became overwhelming, despite using the facilities of a word processor and spreadsheets. To manage the data better and enhance transparency and rigour, the whole data set was transferred into the Computer Assisted Qualitative Data Analysis Software

(CAQDAS) package Quirkos®. Quirkos® was considered appropriate for this research because it provides a variety of search and retrieval tools and the facility to perform comparisons within groups or partners and across groups or partners, and to compare labels, categories, and themes.

It is important to mention that no software, word processor, spreadsheet, or CAQDAS can provide understanding or give meaning to the text; that is the task and skill of the researcher. Any computer program is an instrument that simply manages the data and makes handling of them easier (Burnard 1994; Burnard et al. 2008; Pope, Ziebland & Mays 2000).

The complete data set was transferred from the individual word processor documents into Quirkos® as individual *source files*. This assisted with the continuation of orderly and accessible retrieval of data (Houghton et al. 2015; Ritchie & Lewis 2003). The demographic, health, and medical characteristics of each partner were imported into Quirkos® as *source properties*, which linked directly to the *source files*, allowing the researcher to explore the data in multiple ways, e.g., by gender, age, education, number of CCCs, health professional involvement, and carer status. The initial framework, previously indexed in spreadsheet format (Appendix I) was transferred to Quirkos® as a *Quirk* (label), and an example is depicted in Figure 9.

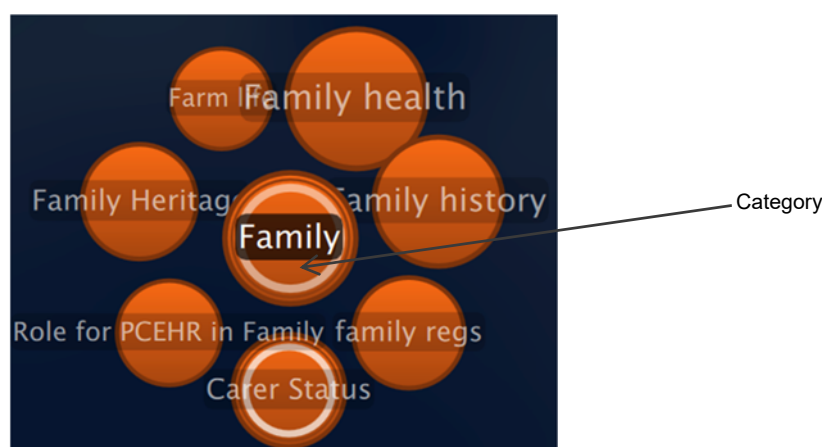


**Figure 9. Example of a label**

As the analysis continued, the researcher highlighted significant words, parts of sentences, or whole paragraphs from the partner and group transcripts in the *source text*, by dragging and dropping the highlighted piece into the *Quirk* (label) that best reflected the content of each passage, or by generating an emergent *Quirk* (label). Each label reflected the group, the partner, their lived illness, their experience of and

engagement with MyHR, and how this might be useful for addressing the research questions.

One of the most important aspects of the data analysis was the flexibility and transparency of data reduction, achieved by comparing and contrasting data and highlighting and grouping similar quotes together. Using a hierarchical arrangement the researcher could distinguish the overall structure, rather than becoming overwhelmed by the abundance of *Quirks* (labels) (Rabiee 2004). The *Quirks* (labels) were further sorted, refined, and charted to categories as depicted in Figure 10.



**Figure 10. The category ‘Family’ charted from the labels**

To assist in indexing labels and charting labels to categories, each label and category required a research-specific description. The descriptions assisted in demonstrating a research-focused understanding of: the word, part sentence, or paragraph that was indexed to a label, why each label had been charted to a particular category, and later, why the category was mapped to a theme. Table 15 demonstrates labels charted to a category and their individual descriptions.

**Table 15. Example of label and category descriptions**

Category	Description
<i>Family</i>	<i>Those individuals who are in some way important to the person calling them their family.</i>
Label	
<u>Family background</u>	Family and the lives of family members have a significant impact on life experiences
<u>Family health</u>	One part of the entire history of a person
<u>Carer status</u>	Anyone who cares, paid or unpaid, for a friend or family member who because of CCCs, struggles to cope without their support.

As the researcher became further immersed in the data, the labels were charted to categories. To ensure appropriate context, the researcher repeatedly checked progress

against the original transcripts, audio recordings, and reflective journal memos and notes. Where some labels initially belonged in more than one category, adjustment of the category was necessary to reflect more accurately the emerging data. This ensured that the data fit in only one category and was not repeated in several. Table 16 displays the narrative indexed to a label then charted to the category *Family*, one partner per row, one label per column.

**Table 16. Example of *Family* category**

	<b>Category-Family</b>		
	<b>Label Family background</b>	<b>Label Family health</b>	<b>Label Carer status</b>
C H. 6	We've two children. A boy and a girl, they are doing very well they've left school I'm not a grandma yet. They're both working, one's in Queensland and (daughter's) down at Huonville. Mum's parents were from here (Tasmania) and both born here in Tasmania of Irish ancestry and Dad's parents were both born in Yorkshire and came out here after the war. Dad was evacuated out here during the war and him and his sister refused to go back when the war finished and so his parents came out here.	My mother is deceased at 82 years she had MS and dementia. Dad's health is good, other than legally blind, he's got a pacemaker, had double bypass	I'm not a registered carer but I do care for my father, who lives on his own.
C H. 13	We live on a mixed farm our grandchildren our 8th generation. Our grandparents were Scottish. We were the first farm to milk sheep, niche veg and poppies. It financially supports one family and one workman. We're currently doing succession planning; produce goes to mainland and Hobart. We also have a mill (flour) ...	My mother sits all day she's developed diabetes and now she has macular and cannot see the bottom of letters and her feet are numb. My dad has macular as well	Informally for my father and mother in-law (and) sister is coming from Japan to help with mum.
C H. 14	Lost both parents in Switzerland due to an accident. Bought back here to the Snowy Mountain scheme by my father's best friends who thought they couldn't have children then went on to have 3 children naturally. They brought me up.... I have a son and daughter living (twins) and an older daughter who died at 43, 2 years ago ... Oh and 4 Grandchildren	and (granddaughter) is a Lymphoblastic Leukaemia survivor. Strong family history of Type 1 diabetes and Hashimoto's	My son is my carer he lives in Fern Tree
C H. 19	Never knew grandparents I'm 4th or 5th gen Aus.	Dad died 10 yrs. ago. Ca stomach and secondary in his 80's. Had a heart attack in his 40's. Mum has lumps on her breast she's alive at 94 yrs. [In] 2014 [son] was diagnosed with Type 2 diabetes	No, I was for my 2nd wife. My wife is now my carer

### **3.4.5.3 Phase 2. Data description**

#### *Stage 4 mapping the data*

Stage 4, mapping the data, was guided by the research objectives. Once all the data had been labelled and categorised it required further refinement. This was achieved by reviewing the data in the categories and making connections to create themes. During this stage, the researcher looked beyond partner and group narratives toward

the label and category descriptions and the developing themes. This offered possible explanations for what was happening with the whole data set. Table 17 displays each label linked to a research objective, and shows how the label charted to a category and finally, how it mapped to a theme. Each description demonstrates a research-specific understanding of a label, category, or theme. Again, this assisted in the labelling, categorising, and mapping of data to themes. Stage 4 is demonstrated and discussed in depth in Chapter 4.

**Table 17. Example of mapped theme**

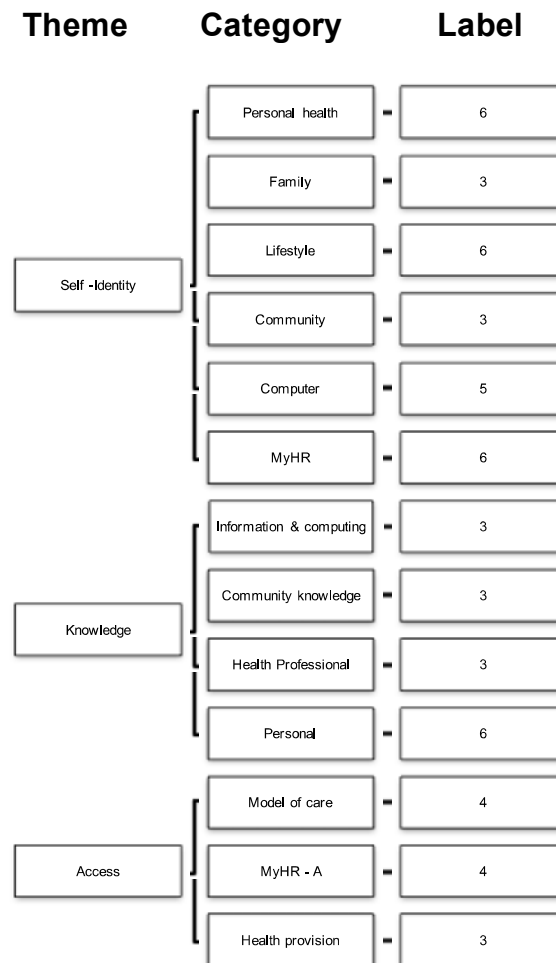
	THEME	Description
	<b>SELF IDENTITY</b>	Understanding and belonging, which have positive or negative affects and effects on physical and mental health and wellbeing
	<i>Category</i>	
	<i>Family</i>	<i>Those individuals who are in some way important to the person calling them their family.</i>
<b>Research objective</b>	<u>Label</u>	
Ro1	<u>Family background</u>	Family and the lives of family members have a significant impact on life experiences
Ro1	<u>Family health</u>	One part of the entire history of a person
Ro1	<u>Carer status</u>	Anyone who cares, paid or unpaid, for a friend or family member who due to CCCs, struggles to cope without their support.

Throughout the data management and description, three requirements were adhered to that retained the essence of the groups and the partner interviews:

- key terms, phrases and expressions were taken from the partners' language;
- interpretation was kept to a minimum;
- no material was dismissed as irrelevant because its inclusion was not immediately clear (Spencer, Ritchie, O'Connor, et al. 2014).

All the data were analysed on the basis of systematic labelling, categorising, and finally mapping. As depicted in Figure 11, the synthesised data were indexed to 55 labels, charted to 13 categories, and mapped as three themes.





**Figure 11. Diagram of data synthesis**

### ***3.4.5.4 Phase 3. Data explanation***

#### *Stage 5 interpreting the data*

Phase 3, data explanation, included stage 5, and allowed the researcher to interpret and be imaginatively analytical by exploring and identifying linkages between the labels, categories and themes as a research community. The process continued to be influenced by the research objectives and the emerging concepts generated from the data. The data and themes were again interrogated, offering possible explanations for what was happening within the data. This generated 16 potential findings, but further discussion found that some potential findings were linked across more than one theme. Scrutiny between the themes resulted in the 16 potential findings becoming nine established findings. These refinements are presented in section 4.4, Table 34. An interpretation of the nine findings is provided in Chapter 5.

### 3.5 VALIDATION AND RIGOUR

This section describes and discusses how research validation and rigour were achieved. The focus of the research was the experience of and engagement with MyHR by people living with CCCs in a rural community. The researcher incorporated the principles of CBPR and involved the research community throughout, while also engaging as a member of the research community. To ensure that the research remained rigorous, the researcher adopted a reflexive approach. Reflexivity is described by Patton (2002) as the researcher accepting and answering a fundamental set of reflexive questions throughout the research process:

- Self-reflexive - What do I know? and How do I know what I know?
- Partner-reflexive - How do those studied know what they know?
- Audience-reflexive - How do those who receive my findings make sense of what I give them?

The way in which the researcher met these requirements is displayed and demonstrated in Table 18, which is adapted from Hansen (2006b); Leal et al. (2015); Rice and Ezzy (1999).

**Table 18. Validation and rigour**

Reflexivity-validation and rigour	How researcher met reflexivity requirements
Adherence to CBPR principles	Prior to commencing the research the researcher discussed the community proposal with their research supervisors, agreeing that the research question suited a participatory qualitative inquiry and that CBPR was an appropriate qualitative methodology for the research focus. Throughout data collection and analysis, the researcher valued and adhered to the participatory philosophy underpinning the CBPR principles.
Transparency	The purposive sampling approach was appropriate for the research question and CBPR methodology. A purposive sampling technique identified partners for their particular characteristics of relevance to the research question. Data collection was achieved in 3 phases using group meetings and semi structured interview techniques to ensure discussion and impartiality. Using a three-phase thematic analytical framework approach facilitated a flexible iterative and systematic method. The interconnected stages provided transparency in a systematic data analysis.
Member checking	To overcome potential biased interpretations the research community approved all transcripts. The group meetings and partner interviews provided appropriate opportunities for member checking which involved comparing and cross-checking the researcher accounts and iterative findings.
Discussion, refinement of thematic framework, and interrelatedness.	Additional to the research community member checking, the researcher and supervisory team extensively discussed labels, categories, and themes as they emerged (peer debriefing). This ensured consistency and accuracy between integration of data and interpretations, refining the hierarchy and discerning the relationships between themes.
Credibility	The researcher worked with or returned to full transcripts rather than working

	only with labels or categories, which avoided separation from the context. All data were evaluated equitably, where contrasting data within and between partners, group or groups, were identified this was displayed and openly discussed.
Use of quotes	Ample examples from the raw data were provided to demonstrate the label/category/theme linkages that formed the thematic framework and provided evidence of how the data built the interpretation.
Comparison with research evidence	Results of analysis were compared with the existing literature to confirm and expand research findings and this was acknowledged appropriately.

### 3.6 ADDRESSING THE PRINCIPLES OF CBPR

This section describes how the research community ensured that the principles of CBPR were addressed. From the inception of the research, the partners and groups were involved in all phases of the research. The research community valued the communication and collaboration they experienced. They were inspired to identify a local rural solution; building support resources and volunteers available in the form of a ‘buddy system’ to support the future roll out of experience and engagement with digital health information and MyHR. Following the conclusion of the data collection, a rural online centre continued to facilitate community-assisted registration and early engagement with MyHR.

The partnership between the university and the community continues to grow. Collaborations between Rural Primary Health Services, Tasmania, now renamed Rural Alive and Well (RAW), and the university continue to measure and assess different aspects of the community and the environment.

It is intended that the findings of the research will be presented to the community via regular community meetings arranged by RAW. Word of mouth will also be used to inform the community about the presentations.

Presentations have been made to interested university faculty members throughout the progress of the research. A further presentation is planned for faculty members interested in the research and research outcome.

Finally, several publications, conferences, and invited presentations have been contributed at state, national and international levels. The titles of the published articles are provided in Appendix A.

### **3.7 RESEARCH ETHICS**

This section recognises the ethical considerations required for the delivery of the research. Conducting the research required research integrity and commitment to elementary ethical principles, respect for all persons, kindness, and justice. Prior to commencement the research acquired ethics approval by the full social sciences Human Research Ethics Committee (H0013781) (Appendix Ci). In addition, annual reports were provided and approval received for the duration of partner and group involvement (Appendix Cii and Appendix Ciii).

An agreement with Rural Primary Health Services Tasmania (Appendix D) was also secured prior to research involvement with the community and subsequently the research community. Finally, the 19 partners were provided with and read information sheets (Appendix E) and signed consent forms (Appendix F), which prior to commencing the research were securely stored for future reference if required. The ethical considerations associated with the research protected the research community from any harm, or perceived harm, associated with their involvement in the research.

### **3.8 SUMMARY**

Chapter 3 has presented the research methodology used in the conduct of this research. The participatory research philosophy and paradigm, characterised by a subjective ontology, extended epistemology, axiology, CBPR methodology, and methods for data collection and a thematic framework approach to analysis were chosen for their inclusive, collaborative processes, which:

- reflected a concern of the partners' community;
- encouraged equitable involvement of the research community throughout the research process;
- allowed the researcher to fully engage in the community;
- met the research objectives, presented in section 1.2.2, and answered the research questions presented in section 1.2.3.

To obtain rich examples of an experience of and engagement with MyHR, thereby gaining meaningful information, and to adhere to the principles of CBPR, the research design required a series of inclusive, practical, and transparent phases. Each phase progressed through iterations of action and reflection: an introduction, three phases of data collection (pre-experience of MyHR, registration and early engagement with MyHR, post-experience and engagement with MyHR), and three phases of data analysis (data description, data management and data explanation).

The research community agreed to the data collection techniques: group meetings, SSIs and the researcher's reflective journal. The data collection tools were audio recordings, a group guide, a SSI guide and live interaction with MyHR as a healthcare user.

To validate the research and uphold ethical integrity, verbal consent and an adherence checklist were reaffirmed on each occasion of data collection. The checklist ensured partner and group consensus, fully informed participation, and adherence to the principles of CBPR.

The research generated large amounts of data, which required transparent, rigorous analysis. The chapter has presented and described the phases and stages of data analysis. The transparent, systematic, thematic framework approach required iterative tasks in the management of raw data, the descriptive process, assembling data in a meaningful way, and preparing the data for explanation. The chapter continued with sections describing and discussing how research rigour and validation were achieved and how the research community ensured that the principles of CBPR were addressed. The chapter finally recognised the ethical considerations required to proceed and progress the research.

Chapter 4 presents the data analysis with respect to providing evidence by linking the evidence to the research objectives outlined in Chapter 1.2.2, with the ultimate purpose of identifying findings.

# Chapter 4: Data analysis

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Chapter 4 presents an in-depth systematic data analysis with respect to identifying evidence and linking the evidence to the research objectives outlined in section 1.2.2, with the aim of ultimately identifying findings. The chapter is organised into the following sections:

- 4.1 provides an introduction to the analysis approach; it briefly revisits the thematic framework approach used for data analysis and reflects on the principles of CBPR;
- 4.2 presents the research community characteristics; this was deemed appropriate to provide context for the responses of partners or groups during data analysis;
- 4.3 presents a transparent, systematic example of the thematic framework analysis, is subdivided into themes and then subsections to provide examples of the narrative indexed to labels, charted to categories, and finally mapped to themes; a summary is provided at the end of each theme;
- 4.4 provides a summary of the themes, and identifies 16 potential findings prior to suggesting nine findings;
- 4.5 provides a summary of Chapter 4 and introduces Chapter 5.

## 4.1 INTRODUCTION

This section introduces the approach to analysis. It briefly revisits the thematic framework approach used for data analysis (see section 3.4.5) and reflects on the principles of CBPR. Data analysis was achieved in three phases using an in-depth process of data management, data description, and data explanation. The process was further refined using five iterative, interconnected stages.

The researcher led the data analysis as a member of the research community, which explored the experience of and engagement with MyHR of people living with CCCs

in a rural community. As outlined in section 3.4.3, the research used audio recordings to collect data from SSIs and meetings of the three groups, plus the researcher's reflective journal. The advantage of using a thematic framework analysis was that the approach could be shaped by *a priori* ideas: the research objectives, research design, and group (Appendix G) and interview guides (Appendix H). It offered a transparent method of indexing labels from which categories were charted and finally mapped to themes, all firmly based on the research community's lived experiences.

To adhere to the principles of CBPR based on the four participatory assumptions that (a) genuine partnership means co-learning, (b) research efforts include capacity-building, (c) findings and knowledge should benefit all partners, and (d) CBPR involves long-term commitment to effectively reduce disparities (Israel, B et al. 2003), the research community were engaged throughout the data analysis. The transparent systematic thematic framework approach used during data analysis achieved this through collaboration of the research community in:

- examining and discussing the data as one humanistic sample presented in the research community's natural setting;
- assembling the data as ideas and feelings expressed in the accounts of the partners and groups;
- exploring the richness and thickness of confirming or conflicting responses within and between partners and group responses to be displayed as a label, a category, and finally a theme.

The SSIs and group meetings facilitated our iterative exploration of responses, discussion of conflicting comments, and agreement on recurring themes. The method of thematic framework analysis provided a systematic, inclusive, and rigorous process.

## **4.2 RESEARCH COMMUNITY CHARACTERISTICS**

This section presents the research community characteristics. This was deemed appropriate to provide context for partner or group responses during data analysis.

Throughout the data collection, the researcher was dependent on the willingness of the partners to not only take part, but also to share their experiences and thoughts about the phenomenon in question. The researcher considered it a principle of CBPR that they should listen to the stories about CCCs to show respect and gain the trust of the partners. The detailed stories provided perspective about contextual insights toward understanding the partners' experience of and engagement with MyHR.

Nineteen partners were recruited into the research. Their characteristics are displayed in Table 19. The average age of the research community was 62.4 years and more than two-thirds of them were women. This is somewhat consistent with the gender ratio (the number of males per hundred females) in Australia, which was recorded as 98.5, and 97.7 in Tasmania (ABS 2016c). The partners reported their cultural identities as Australian, British and European.

The medical characteristics of the research community revealed that more than half of them described four or more CCCs, and almost three quarters had more than four current professional healthcare providers. Less than half the partners identified having any carer support. The self-reported carers personally described having more than four CCCs.

All partners had had experience of and engagement with computers in either or both a personal and a professional capacity. All partners stated that they had internet access via a 'landline'. Fifteen partners used the internet daily at home, and three accessed the internet outside their homes, either at the community online centre, LINC, family or friends. One partner reported no current use of computers.

**Table 19. Partners' self-reported characteristic information**

Characteristics	n (%)	Characteristics	n (%)
<i>Gender</i>		<i>Number of CCCs</i>	
Female	13 (68.4)	2	6 (31.6)
Male	6 (31.6)	3	3 (15.8)
		4	3 (15.8)
		5 or more	8 (42.1)
<i>Age years</i>			
40-49	3 (15.8)		
50-59	4 (21)		
60-69	8 (42.1)		
70-79	3 (15.8)		
80-89	1 (5.3)		
<i>Education</i>		<i>Number of health professionals involved in delivery of care</i>	



Less than high school	8 (42.1)	2	5 (26.3)
High school graduate	3 (15.8)	3	0 (0)
College graduate	1 (5.3)	4	7 (36.8)
University graduate	7 (36.8)	5 or more	7 (36.8)
<i>Ethnicity</i>			
Australian	14 (73.7)	<i>Carer Status</i>	
British	3 (15.8)	Carer	4 (21)
European	2 (10.5)	Cared for	3 (15.8)
		Nil	12 (63.1)
<i>Computer &amp; Internet availability</i>			
Home, work or both	15 (78.9)		
Family, friend or community (online centre, LINC)	3 (15.8)		
No use	1 (5.3)		

### 4.3 THEMATIC FRAMEWORK ANALYSIS

This section presents a transparent, systematic example of the thematic framework analysis. The section is subdivided into themes and divided into subsections to provide examples of the narrative indexed to labels, charted to categories, and finally mapped to themes.

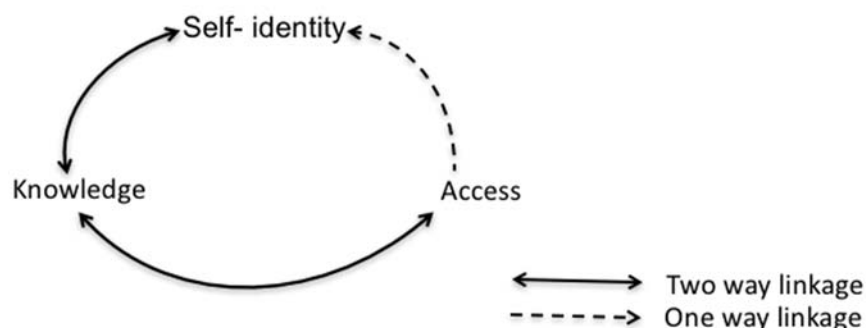
Data analysis of interviews, group meeting accounts and the researcher's reflective journal showed three emerging themes: self-identity, knowledge, and access. Table 20 provides a brief description of each theme, mapped from the categories and charted from the labels, which were indexed from partners' interviews and group meeting accounts. An in-depth description is provided during the introduction to each theme.

**Table 20. Brief description of each theme**

THEME	Description
<b>Self-identity</b>	Understanding and belonging, which positively or negatively affect and effect physical and mental health and wellbeing
<b>Knowledge</b>	Familiarity, awareness or capability with or of something or someone gained through experience and education
<b>Access</b>	Connects, provides a flow of information between subjects and objects

The three themes interrelate the way the partners and groups as a research community perceive and connect their personal and conceptual experience of living with CCCs in a rural community with their experience of and engagement with MyHR. **Self-identity** is a dynamic process involving the ongoing accumulation of **knowledge**; a work in progress. **Knowledge** is a dimension that affects the development of **self-identity**, hindering or helping growth; **self-identity** influences

the search for and use of **knowledge**; this may not always be balanced. **Access** to **knowledge** influences and sustains **self-identity**; similarly, **knowledge** offers **access**, helping to shape **self-identity**. Figure 12 represents the theme linkages.



**Figure 12. Three theme linkages**

In section 4.3, to assist discrimination between labels, categories and themes, different type formats have been used: a label will be presented underlined, a *category* presented in *italics*, a **theme** presented **emboldened**.

Each of the three themes: **self-identity**, **knowledge** and **access** carry a research context description, mapped from a *category*, described and charted from a label. Each label carries a description and has been indexed from a word, part sentence or paragraph that it represents. Each theme section incorporates subsections, which commence with a figure introducing the *category* linkages and continue by providing an in-depth description of how they collectively map to a **theme**. The subsections contain tables, which link the relevant research objectives (identified in section 1.2.2) and provide a brief description of each label, *category* and **theme**. Following the table, the process of linkage of the indexing labels to charting *categories* is presented.

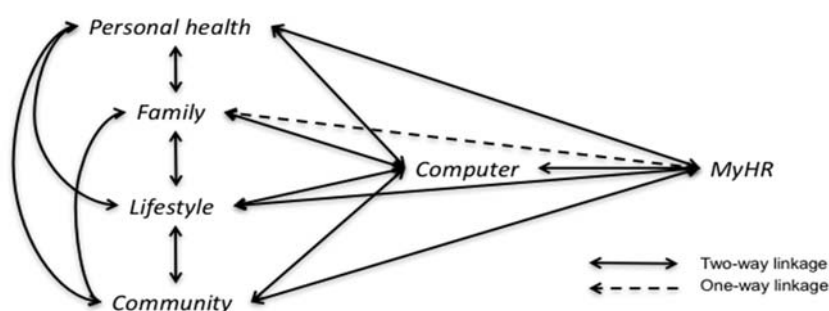
#### 4.3.1 Self-identity

THEME	Description
<b>Self-identity</b>	Understanding and belonging, which positively or negatively affect and effect physical and mental health and wellbeing

**Self-identity** mapped by recognising and valuing all partner and contextual characteristics within the research community. In the context of this research, it is defined as understanding and belonging, which has a positive or negative impact on physical, psychological and social health, and wellbeing. **Self-identity** is fluid,

valued, and considered as worthwhile across the research community. **Self-identity** can be masked according to what a partner wants others to know or think. There is a need to belong to a community, to be understood and to contribute. Equally there is a sensitivity, a reluctance to being stereotyped by physical and psychological health concerns.

**Self-identity** was mapped from six categories, *personal health*, *family*, *lifestyle*, *community*, *computers* and *MyHR*. All of these categories co-relate and collectively map to **self-identity**; the linkages are depicted in Figure 13. A brief description of the individual categories and labels they were charted from follows. An in-depth description is provided in the subsequent sections as the labels are charted to categories and mapped to themes.



**Figure 13. Self-identity category linkages**

Within the theme **self-identity**, it was found that *personal health* influences interaction with *family*, *lifestyle* and *community*, the ability, use and utility of *computers* and experience of and engagement with *MyHR*.

The changing level of physical, psychological, and social health and wellbeing of the partner's *family* directly affects and effects their *personal health*, *lifestyle*, *community*, and use and utility of *computers*. The relationship between *family* and *MyHR* is complex: although the partners can tell *family* about *MyHR*, *family* cannot directly access the partner's *MyHR* unless registered as carers on *MyHR*. However, *family* may influence the partner's experience of and engagement with *MyHR* by offering positive or negative responses and attitudes about their perceived experience of or engagement with *MyHR*.

*Lifestyle* can be directly affected or directly affect the *personal health*, *family*, *community*, physical, psychological and social health and wellbeing of a person

living with CCCs, which can in turn affect their use and utility of *computers* and their experience of and engagement with *MyHR*.

*Community* can be directly affected by or directly affect *personal health* and *family*, physical, psychological, and social health and wellbeing. The use and utility of *computers* and the experience of and engagement with *MyHR* can be influenced or influence one's *community*.

*Computer* can affect *personal health*. People living with CCCs, *family* and *community* can develop alternative communities, search for, send, and receive information, provide for a connection with others and *MyHR*. *Computer* has potential, qualities, and equally, limitations.

*MyHR* promises an opportunity to be empowered, engage, informed, and directly involved through *computer* in *personal health*, *lifestyle* and healthcare provision, within their *family* or *community*.

#### **4.3.1.1 Personal health**

The category *personal health* describes and offers understanding and awareness of how the person is affected and effected by their physical, psychological, and social health and wellbeing requirements. Linking the categories shows the *personal health* limitations, potential, and qualities of a person living with CCCs, their influence and interaction with *family*, *lifestyle*, and *community*, their use and utility of *computers*, and their experience of and engagement with *MyHR*.

During phase one, in response to the interview question 'Tell me about yourself and your health', the partners narrated their stories and took the opportunity to express their needs and their understanding of themselves and their health. Phase one group meetings also offered narrative that indexed and charted to *personal health*. Analysis indexed the data to six labels, charted to the category *personal health* and mapped to the theme **self-identity**. These are presented in Table 21, which links them to the research objectives, and provides a brief description of each label, category, and theme. A research perspective and an example of narrative follow.

**Table 21. Personal health**

	THEME	Description
	<b>SELF- IDENTITY</b>	Understanding and belonging, which positively or negatively affect and effect physical, psychological and social health and wellbeing
	<i>Category</i>	
	<i>Personal health</i>	<i>An understanding and awareness of how a person is effected and affected by their physical, psychological and social health and wellbeing requirements</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.3	<u>Age</u>	How a partner sees themselves, a length of time, in the context of health
Ro1	<u>General health</u>	A partner's perception of quality of life or state of physical and mental wellbeing
Ro1.3	<u>Effect of having CCCs</u>	Diminished control over life and future, lack of self-confidence, disruption, how CCCs impact on partners' quality of life
Ro1.3	<u>Effect of rural living on CCCs and personal health management</u>	The consequences that living in a rural location has on the partners' CCCs, whilst managing one's personal health and information all of which directly influences the quality of one's own care
Ro1.2	<u>Personal health goals</u>	Thinking positively about the future, a motivation
Ro1.3	<u>Personal privacy</u>	The right to determine whether, when, how, and to whom, one's personal details are shared

There was an acknowledged decline in health that comes with age; a need to balance the ageing processes with an acquisition of experiences, information, and understanding, which should be shared to benefit others:

I'm not too bad for my age but I'm nowhere near as good as I use to be ... [but] the breadth of knowledge that I've gathered over the years will be of great use to others (O4).

However, contrasting evidence is provided: some partners are aware of the ageing process and although in the past had shown a willingness to share information, they now identify with a lack of patience with others:

You know what ... as I get older I haven't got the umm, once upon a time I would have stood or sat and explained things, I haven't got that in me anymore, patience or energy, I just think you know just go away (CH14).

There is an awareness of general health. The research community narrate an awareness of a reduced level of fitness. These responses were not surprising because they were all personally, or had been made aware of, the affect and effect living with CCCs were having on their declining level of general health:

I'm reasonably healthy, but I'm very unfit (CH6).

I don't do too much stuff, I become tired quick, I'm worn out before I start (O2).

It's time that's difficult to juggle ... (I need) to get life back on track and improve [my] lifestyle (L1).

The multiple CCCs reported by all the partners is recognised as the effect of having CCCs, which, frustrates their ability and availability to access social, recreational, physical, and cognitive stimulation:

I try to participate, as much as I can, for the company I feel useless honestly, I stopped driving. I shall remain active with the [lifestyle program] .... I go to the access centre if I need a computer. I may not be as fast. I don't see it ... I need a decent screen and enlarged typeface (CH14).

To enable appreciation of the challenges and the effect of having CCCs experienced by all the partners, the data draws attention not only to the demographic, rural, and CCCs challenges but also the multiple CCCs. This highlights the importance of the partners' perception of their need for MyHR:

One person, one health note (CHFG2).

The partners freely narrated their personal health information. However, because of the comparatively small number of partners in the research, the information has been anonymised to allow them to remain anonymous and to remain within the ethical parameters of the research. The anonymised data are tabulated and displayed alphabetically by body system in Appendix J.

The effect of having CCCs on lives and lifestyles provides personally significant evidence of how CCCs affect and effect quality of life. Although the partners are aware of the effect of having CCCs, motivation and optimism is still present:

[I]nstead of whingeing, I think get on and have a go first. When I do the exercise I feel like I could go for miles. Well that's when I think that's perfect (CH22).

However, contrasting partner stories tell of diminished control over their life and future, lack of confidence, and the disruption that the multiple CCCs has on their quality of life; the effect of having CCCs on *personal health*:

I feel useless honestly I stopped driving ... I cry a lot now, it's pulling me down. I don't retain well, I've had 2 strokes, my short-term memory isn't great. I was once very cerebral, now I feel a nought (CH14).

The effect of rural living on CCCs and personal health management was indexed from discussions regarding the perceived value of MyHR. The effect of rural living on CCCs and personal health management can affect a person's ability to manage appropriately the transitional needs of their CCCs; this may lead to a decline in their CCCs:

[T]he remoteness can make it hard to access medical information (CH23).

I'm finding because I'm out here I'm not talking to people as much, I feel I'm talking into myself (O1).

I am fairly fit, but not every day if [CCCs] is playing up that is so debilitating I can't tell you .... We haven't been able to go into the gym ... it's an hours trip just to get there so we can't just go down all the time because we can't afford another truck (CH22).

As outlined in section 3.4.1, Table 9, the research inclusion criteria required all partners to have two or more CCCs. In reality, when the partners were asked to talk about themselves, their health, and who is involved their healthcare provision, more than half of them comfortably described living with four or more CCCs, and almost three-quarters were currently engaged with more than four professional healthcare providers; these details are tabulated in section 4.2, Table 19. The identification of multiple CCCs and the complexity of the interactions between the partners and their healthcare providers requires holistic understanding, accurate communication, and commitment to engagement.

Personal health goals can support a positive personal awareness of psychological health and an improved personal and community understanding of health requirements and disease processes. When asked an emergent question 'what are your personal health goals?' The following partner responses were narrated:

[I]mproved state of mind (CH14).

[T]o walk without canes and pain reduction (CH19).

[K]eep up with grandson who wants to keep going. Try to eat well (L2).

[N]eed to keep active ... and generally feel better mental and physical (O4).

All partners comfortably articulated personal responsibility for physical, psychological, and social long-term health-related modification goals and practical actions:

I saw a notice for Nordic walking, I had a set of poles because I have a rocky road to walk, so when I saw that I thought great ... I play mah jong ...with a self-help group, a new game new people, learnt to drive ... my mental health and friendship is very important (CH13).

Personal privacy describes the discretion, respect, and dignity afforded to all aspects of personal details, including how those details are shared. One partner expressed sensitivity to the stereotypes that others may have about illness or disability and a preference not to divulge information about personal illness or disability within their community:

I keep very private because a lot of people say this, this, this and they want to know more. I keep a lot of things to myself (CH14).

Other partners revealed themselves as more open, liking to be involved, sometimes to their detriment by failing to always respect others' privacy choices:

[De-facto] was always a private person but I like to be out there ... it does cause some strife sometimes. It doesn't matter what you do, if you think you pleasing everybody you're not (CH22).

The group meetings, with live access to experience MyHR, voiced that personal privacy should be valued, but equally, that once personal health information has been agreed to be shared, health information held by a third party should be shared with them. Health information needs to be shared and available:

I think it's important to have privacy and security but once I've said I'm happy to share my [CCCs] stuff then I would like my [CCCs] stuff shared with me (CHFG1).

I don't want it [CCCs] to be private. I want it [CCCs] all to be open where I go (OFG1).

However, poorly explained or misunderstood messages can create ambiguity:

[T]hey could get the normal things, what I have wrong with me diseases and all that, but anything private they've got to fight me (CHFG1).

Personal privacy is a personal choice. In the context of sharing health information, the research community want to be invited to share as much or as little information as they understood or recognise to be necessary. The sharing of personal information requires well-defined, concise details about what information is being shared with whom. Taking into consideration opponents to MyHR often do so on the grounds of personal privacy the research community contest this argument. They associate the use of jargon, ambiguity, and the presumption of understanding leading to confusion



on the part of the recipient, in turn leading to resistance to and failure of the introduction of any new model of healthcare provision.

The data collected from the interviews and group meetings were indexed to six labels: age, general health, effect of having CCCs, effect of rural living on CCCs and personal health management, personal health goals and personal privacy. Each label was charted to the category *personal health*. *Personal health* charted the positive or negative impacts on everyday life of living with CCCs. This is demonstrated by how a person living with CCCs understands, communicates, and engages with their transitional health and experiences their environments and social relationships. What may appear insignificant everyday contacts and choices affect and effect **self-identity**. The category *personal health* offers a personal and research community understanding of the importance of physical, psychological, and social health and wellbeing for a person living with CCCs in a rural community. It recognises the potential and qualities of a person in *family*, *community*, *lifestyle*, use and utility of *computers*, and experience of and engagement with *MyHR* as a dynamic concept. As such, *personal health* can be maintained or expanded or can require re-creating **self-identity**.

#### 4.3.1.2 Family

The category *family* describes those people who are important, who the research community agree to refer to as *family*. They share *family* culture, values, dynamics, experiences, opportunities, and consequences. Linking the categories shows how the changing level of physical, psychological, and social health and wellbeing of *family* directly impacts on *personal health*, *lifestyle*, *community*, their use and utility of *computers*, and their experience of and engagement with *MyHR*.

In response to the phase one interview question ‘Tell me about your family’, the partners comfortably narrated experiences that analysis indexed to three labels, charted to the category *family*, and mapped to the theme **self-identity**. These are presented in Table 22, which links them to the research objectives with a brief description of each label, category, and theme. A research perspective and an example of narrative follow.

**Table 22. Family**

	THEME	Description
	<b>SELF-IDENTITY</b>	Understanding and belonging, which positively or negatively affect and effect physical, psychological and social health and wellbeing
	<i>Category</i>	
	<i>Family</i>	<i>Those people who are important in some way to the person who calls them their family</i>
<b>Research objective</b>	<u>Label</u>	
Ro1	<u>Family background</u>	Family and the lives of family members have a significant impact on life experiences
Ro1	<u>Family health</u>	One part of the entire history of a person
Ro1	<u>Carer status</u>	Anyone who is a paid or unpaid carer for a friend or family member that because of CCCs, struggles to cope without their support

Family background indexed the values and experiences that contribute to and influence the partners positively or negatively. It was important to develop understanding and trust with each partner and group early in the data collection process. Gaining a sense of their family background demonstrated a personal and contextual interest, deepened their story, and provided research insight into how they are affected by and effect the interaction and support they have from *family*, and ultimately their experiences of and engagement with *MyHR*. Partners spoke in depth of diverse cultural family backgrounds that had offered them opportunities:

We've two children. A boy and a girl, they're doing very well, they've left school. I'm not a grandma yet. Mum's parents were ... both born here in Tasmania of Irish ancestry and Dad's parents were both born in Yorkshire and came out here after the war Dad was evacuated out here during the war and him and his sister refused to go back when the war finished and so his parents came out here (CH6).

[O]ur grandchildren are 8th generation. Our grandparents were Scottish. Both my parents are still living. I have one sister (younger). She's lived in Japan for 40 years. My parents were born on the NW coast. Then when I had 1st grandchild they moved to Bothwell, Father is mother's carer, I am a clone of my mother, it would be interesting to look at my sister's lifestyle. I have two children one living, [son] died in 2011, May ... (CH13).

We're the original [Smith], my grandfather was a [Smith], came from Bream Creek, there were five [Smith] brothers and they grew up, I don't know how they ended up out here. There's a book written about it, Dad's family was a convict from England and one of them ended up a policeman. This is mum's family, it's a book on the [Smiths].... Mum and Dad are actually second cousins. Through Dad's mother ... She wrote this book, she grew up in [local village] (L2).

The responses to the interview question ‘Tell me about your family’ demonstrated a trust-centred relationship in the research community: the partners had no hesitation in sharing their family background in detail with a sense of belonging. One partner, although denying much knowledge of their ‘birth family’ provided great detail:

I don’t know much I was adopted I grew up with ... two brothers and a sister [adopted]. My brother [adopted] drowned in a sailing boat off the northeast coast ... I grew up with them in [town]. My biological mother's name was [withheld]. I don’t know who my father was, she didn’t either. She died when she was 67, I think, in New Zealand. I was first then she had two other daughters then she went to New Zealand got married and had three more kids but that’s all I know. Oh, she had arthritis very badly. On her father's side they all live to a long age and his side of the family had dementia. Her mother's side they were also long-lived and they had a lot of diabetes in the family but that's all I know about them, the biological side, but I forget about them because they weren’t my family really. (CH20).

The researcher’s reflective journal concurred, noting that ‘the willingness to share such a depth of family history is humbling at this early stage in the research’.

The values and experiences indexed as family background revealed research community stories as diverse positive or negative opportunities that brought about a sense of belonging.

Family health can significantly affect personal development and one’s own health and wellbeing. Below, a partner provides an example of the consequences of family health: they viewed their role in the *family* as the main carer, not by choice but by necessity, a role they had to ‘escape’ from; the narrative echoes bitterness. They related the interview question ‘Tell me about your family’ to a carer role:

[Mum] died to get away from Dad. Dad was a cranky old man. I also cared for my neighbours and aunt and worked full time. It was a bad time. It’s part of the reason we escaped. My brother, is well in QLD, had nothing to do with all the caring. I just said I can't do it anymore. I actually get on better with [brother] since mum died. I use to telephone home but he [Dad] didn't want to know. I had had enough. I was ready for my life. I have a daughter in QLD and 2 grandsons all well. My daughter struggles on her own she's studying on the gold coast. She’s desperate for money. We try and help (CH23).

The bitterness is also evident from the researcher’s journal note recorded at the time ‘[CH23] was angry when asked about family health, this question requires great sensitivity and listening skills’.

The research community, already burdened with the everyday responsibility of living with CCCs, were aware of family health issues and the lifestyle changes they (the family) have made, adding to the psychological burden. The partners gave reasons for changes the family had made in their lifestyle, claiming that each person had changed because of their diagnosis of CCCs, i.e., because of a health implication rather than a preventative lifestyle choice:

[M]y husband stopped smoking because of [CCCs] (L2).

[H]e's top the class [CCCs changes in monitoring and self-care] and also he's given up cigarettes now, he's been smoking for 50 years, he had to (O1).

The consequences and dynamics of family health, i.e., how the research community identifies their position or role in the *family* as carer, parent, grandparent, sibling, or child, directly affects and effects their *personal health*. When the physical and psychological health of the *family* were discussed, partners already burdened with CCCs identified with *family* health issues and the health choices and changes that *family* members had to make, assigning the reason for the changes as their CCCs rather than as a preventative health choice.

As an emergent question, the research community were asked if they 'cared for anyone or if anyone provided care for them?' As shown in section 4.2, Table 19, less than half identified as having any carer support. On an everyday basis, people living with CCCs in a rural community claim to look after themselves, and the daily decisions they make impact their quality of life.

Carer status identification and indexing acknowledges that many informal carers are *family* members, whose caring role is overlooked and unclear; their everyday role is underestimated and undervalued, as is their broken sleep, lack of days off, and caring responsibilities. When a carer is involved it is often as a health advocate, meaning that there is a requirement for not only the person living with CCCs but also their carer to understand and be informed regarding the healthcare provision for the person living with CCCs. All those partners who acknowledged taking on the role of carer each also carried the additional burden of four or more CCCs:

Apart from the asthma and sinus ... I mean I do have BP but I'm very unfit ... I'm not a registered carer but I do care for my father who lives on his own and is legally blind but he looks after himself ... but I do go down and take him where he needs to go to all appointments and things like that and make sure his safe (CH6).

During phase one of data collection, those in a caring role did not identify with the potential supporting role of MyHR, however the narrative changed during phase two and phase three of data collection:

From a carer perspective, she lost her voice. I had to represent her that [MyHR] would have been incredibly useful. To see and contribute to a health record I agree wholly (CH23).

The research community narrated an awareness of the informal, invaluable support their *family* provided, but when asked whether they ‘cared for anyone or if anyone provided care for them?’ most did not identify their *family* as carers. In a rural community, people living with CCCs are extremely vulnerable; without the support of their *family* they would struggle to remain in their community:

My son and grandson are really good; they do all the heavy stuff. I had trouble with my landline. [Phone] been out of order and taken three weeks to fix. My son tried to keep ringing them to tell them it was out of order and one guy told him well we can’t do anything about it without her permission so he said well you ring her so the guy said oh her phones out of order. [Son] said that’s what I’m trying to tell you (CH20).

Those partners who unconditionally assumed the role as carers eventually became overwhelmed and ultimately needed to distance themselves. Adoption of carer status within *family* is often unquestioning of the responsibility the role carries or how it may affect or effect physical and psychological health, lifestyle, or quality of life. Others unaware of their carer status valued *family* support; however, this support was not recognised as carer support.

The data were indexed to three labels: family background, family health and carer status. These were charted to the category *family*. *Family* charted the importance of those people who are referred to as *family*; their values, dynamics, experiences, opportunities, and consequences, personal qualities, the culture they are born or develop in, a desire to belong and feel connected, who impacts this, who they know themselves to be, and how they recognise how they belong. *Family* experiences affect or effect *community*, *lifestyle*, *personal health*, use and utility of *computers*, and experience of and engagement with *MyHR* as a dynamic concept. *Family* can maintain, expand, or require **self-identity** to be re-created.

#### 4.3.1.3 Lifestyle

The category *lifestyle* describes the partners' interests, opinions, and behaviours, and where and how they live. *Lifestyle* charted the research community's thoughts, way of life, and values. The experience of coming to terms with living with CCCs, such as inability to work, mobility restrictions, or less ability to participate socially, can result in an altered *lifestyle*. Linking the categories shows that *lifestyle* has direct impacts, positive or negative, on a person living with CCCs' *personal health, family, community*, their use and utility of *computers*, experience of and engagement with *MyHR*.

During phase one and three of data collection, at interview, the partners comfortably narrated experiences and opinions that analysis indexed to six labels, charted to *lifestyle*, and mapped to the theme **self-identity**. These are presented in Table 23, which links them to the research objectives and provides a brief description of each label, category and theme. A research perspective and an example of narrative follow.

**Table 23. Lifestyle**

	THEME	Description
	<b>SELF-IDENTITY</b>	Understanding and belonging, which positively or negatively affects and effects physical, psychological and social health and wellbeing
	<i>Category</i>	
	<i>Lifestyle</i>	<i>The partner's interests, opinions and behaviours and where and how they live shapes who they are</i>
<b>Research objective</b>	<u>Label</u>	
Ro1	<u>Employment</u>	Success and conflict occurs, memories are formed that may shape and reshape identities
Ro1	<u>Environmental consciousness</u>	Surroundings can have a tremendous impact on personal perception
Ro1	<u>Relationships</u>	Partners have different expectations shaped by their unique family relationships
Ro1	<u>Move to Australia or Tasmania</u>	The cultural change experiences
Ro1	<u>Benefit of rural lifestyle</u>	A culture of family, community kinship and improved quality of life
Ro1	<u>Reason for living rurally</u>	A lifestyle choice defined by rural living

Understanding the partners' stories required a thorough understanding of their background, which included asking about school attendance and 'past or present employment'. Past or present employment is integral to *lifestyle* and provided some indication of their physical and cognitive ability. All partners were working or had

worked full- or part-time until retirement age. The responses are classified as professional, skilled, or manual employment.

The responses were diverse. More than one-third of partners had graduated from university and described using their advanced knowledge to follow a professional career:

I went to, [University] and did Mathematics degree. Whilst at [University] part time I was a school teacher for one year .... Then a job with [Research] Division in the late 70s and retired from them in 2003 .... I've done a lot of research in [subject] it is my career... [Now] I edit the journals and the annals of [subject] from home (CH11).

More than half had been or were employed in positions where a skill or further education were required:

I did apprentice butcher... worked as butcher. Left Meat industry went into hotel business and worked in that. Then liquor stores, then meat industry, then hotel industry again (O2).

Two partners had been or were manually employed:

Worked in Fruit and Veg Shop. Courier boy on my bike, I had no vehicle licence. Then I got a licence and started driving cars then trucks. That happened for a time. Then I took up car detailing and had my own business for a long time. Then trucks again. Then vegetable farming .... Continued for a while and doing some cows carried on doing a bit of farming (CH19).

The label environmental consciousness was indexed from those partners in the research community who choose to live in rural environments and regard it as being an important part of their *lifestyle*:

I cycle ... I don't smoke, I grow my own veg. I do try to live a clean life (CH28).

We try not to leave such a big footprint. All our house is made out of recycled things that other people don't want and we just try to keep. We're so lucky we can grow our own veggies. It's a life work here (CH22).

Environmental consciousness included narrated beliefs and engagement in *lifestyle* and *community* activities that consume fewer resources and produce less harmful waste. They believed that *computers* and *MyHR* offer the possibility of developing their personal and contextual beliefs by using products and services resourcefully. However, the researcher's reflective journal note at the time challenged those beliefs,

suggesting that ‘the resources required to sustain ICT may have an equal impact on the environment’.

Relationships were charted as a *lifestyle* choice integral to the partners’ personal journey. Some partners briefly answered the enquiry regarding relationships; others chose to provide a detailed narrative. Committing to personal relationships is long-term, a personal *lifestyle* choice:

I’m widowed my second husband was high up in the military, in [country], I lost him 10 yrs. ago which is hard. My 1st husband gave me away at my second wedding, [he] died last year; I could let go ... (CH14).

Divorced, I came out here [Tasmania] and got married in 2002 she'd been widowed quite young with 2 adult boys .... Turned out she was possessive ... it wasn't until 2006 I found out. I was in a good position. I hadn't had a marriage of convenience ... I'd already acquired permanent residency by that stage so I moved out but she divorced me, I was still trying in a way ... (CH28).

Move to Australia and/or Tasmania was charted to *lifestyle* as a cultural and social shift, a change experience that affected and effected *lifestyle*.

The partners identified with many communities and *lifestyles*, making each important at different times in a personal journey. For example, some revealed an international *lifestyle*:

Born in Switzerland brought back to Australia at 2yrs. [Adopted] by my father’s best friends, returned to Europe and did some schooling over there then returned to Australia (CH14).

[C]ame out of Australia ... at 28yrs ... I went back in 1988 and came back in 2012 working in England or Scotland [then] back out to Australia in 2012 continuing to work as a [profession] and further education (CH16)

Others narrated a city-based *lifestyle*:

[Wife’s] job ... was killing her so I finally talked her into retiring early we sold everything up and bought a caravan and with our four wheel drive, put furniture in storage and drove off around Australia for 18 months, before we came over to Tas we always intended to complete our journey in Tas to live. I had never been here before, [wife] had 40 yrs. ago (CH 19)

or an ancestral *lifestyle* and country-based *lifestyle*:

We live on a mixed farm our grandchildren our 8th generation. We were the first farm to milk sheep, niche veg and poppies. It financially supports one family and one workman,



we're currently doing succession planning, produce goes to mainland and Hobart; we also have a mill [flour] (CH13).

As an emergent discussion about the community, the partners were asked to share what they thought the benefit of rural lifestyle was. They comfortably narrated their varied opinions, at times providing contradictory reasons:

[It's] easier in the city to access all the services .... Walk more in the city, you don't want to lose your parking space. Rural lifestyle is more manual but then it depends on the rural job. In the city you join the gym and do more steps, and everybody expects it .... I love the space, no neighbours to speak of the only real advantage. The kids are free to run around without too much hovering. City experiences have to travel a lot (CH1).

Country much better, we're more active rural, especially farmers. I'm not that active, I'm a craft person. But I would say rural are much more active because they're outside much of the time. Lifestyle, I prefer rural. They [city] get theatre sort of things, but in town the phones never stop ringing. They [phones] don't work up here .... But when my sister visits from Melbourne, her phone never stops. If it's not a phone call it's a message or an email. I'm busy shearing and calving and then other quiet times you can get things done. Craft fairs get very active. I love the country, always have (CH6).

There was uncertainty related to the identification of both opportunities and limitations indexed as benefits of a rural lifestyle. The partners narrate the benefits of a rural lifestyle as a sense of space, security, less pressure, and peace. They recognise its limitations as periods of inactivity and isolation:

I have met some beautiful people because, I think because they're not crammed up in the 'rat trap' or 'warrens' of urban developments. It's a natural environment. People out here, might be grumpy, but generally they're very open, it's the cleanest air (CH28).

[The] tension can be there in rural and city it's just a different type. I find, to me a city [person], why would you live in the city when you can live out here? (CH19).

[W]hen we decided to sell up and go, we had a mortgage I was resistant. The day I told them I was quitting was the best. I threw my watch away .... We now have our lives, we can get involved if we want, and peace...compared to living in town and I've lived in both some of that is a lot of exercise to and fro from work...I don't know there's a lot of aspects but city people tend to be a lot more stressed, generalising (CH23).

Living in a rural environment is not always a conscious, voluntary, or personal decision. Family, relationships, employment, and heritage have influence.

Reasons for living rurally emerged from the discussion about the benefit of a rural lifestyle. There were varied reasons for living rurally: an opportunity for the children, partners' career, heritage, and personal choice of a way of life, making a conscious family decision to bring up their children in a rural environment:

a change of lifestyle from Brisbane so I wouldn't have to work when we had children (CH1).

or following spouse employment and their heritage:

I got married to a farmer. I grew up in country. [Town] was country in those days (CH6).

[H]usband worked on the farm and the hydro (CH21).

[A]ll my ancestors were farmers or shepherds all that, so I married my husband [a farmer] (CH13).

or *lifestyle* choices:

[B]ecause I love it, I have always had space to get out; I grew up with space to get out (CH28).

[T]he lifestyle the peace relaxation and not sitting on every bodies door step (CH19).

I'm retired, I'm a hermit (CH20).

[B]ecause they're [city life] rushing all the time, rural calmer. We've done that and don't want to do it again (CH23).

The data were indexed to six labels: employment, environmental consciousness, relationships, move to Australia or Tasmania, benefit of rural lifestyle, and reason for living rurally, which charted to the category *lifestyle*, offering understanding of a personal journey, way of life, and values. *Lifestyle* charted interests, opinions, and behaviours; where and how the partners live shapes who the partners are. *Lifestyle* categorises a way of life, shaped by *personal health*, *family*, and *community*. Coming to terms with the impact of living with CCCs on *personal health*, *community*, *family*, use and utility of *computers*, and experience of and engagement with *MyHR* as a dynamic concept results in an altered *lifestyle*, which can maintain, expand, or require re-creating **self-identity**.

#### **4.3.1.4 Community**

The category *community* describes who or what a partner is as I or we within a community. *Community* is a group of people living and sharing similar experiences and situations with similar characteristics. *Community* provides a connection, a sense

of belonging, a network, and a cultural personality. Linking the categories shows that *community* directly impacts, positively or negatively, on the *personal health, family, and lifestyle* of a person living with CCCs, A person's use and utility of *computers* and their engagement with and experiences of *MyHR* can be influenced by or influence their choice of *community*.

During interviews and group meetings in phase one of data collection, the partners comfortably recounted experiences and opinions that analysis indexed to three labels, charted to *community*, and mapped to the theme **self-identity**. These are presented in Table 24, which links them to the research objectives and provides a brief description of each label, category, and theme. A research perspective and an example of narrative follow.

**Table 24. Community**

	THEME	Description
	<b>SELF-IDENTITY</b>	Understanding and belonging, which positively or negatively affect and effect physical, psychological and social health and wellbeing
	<i>Category</i>	
	<i>Community</i>	<i>A sense of belonging, a network, a cultural personality, a connection</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.3	<u>Friendship</u>	Describing themselves according to their role within, outside of or between friendship groups
Ro1.2	<u>Opportunity</u>	Involvement with a community network, resources
Ro1.2	<u>Hobby</u>	A personal enjoyment, a skill, a choice, an action essential for a sense of usefulness, wellbeing, pride, confidence, esteem, satisfaction

Friendship was valued; the label indexed the importance that friendship plays in supporting mental and emotional wellbeing and personal relationships:

My friends are very important to me, for my mental health...they're fantastic (CH13).

[S]ince I've been here he [husband] knows more people in the village because I like to say hello and I love to be involved in helping in the community (CH22).

The opportunity provided by local resources was acknowledged and valued as supporting the maintenance of personal health and wellbeing by providing opportunity, encouragement, and involvement that extend beyond the family:

If I'm eligible I go; they [community outings] didn't use to be there. I've always been social. I go to the day centre, on Saturday trips, shopping. Family not so much. I go out at every opportunity (CHFG3).

I enjoy retreat, we meet up once or twice a year and we went on the Christmas parade, then we had a meal at somebodies place, and Nordic walking, outings to towns, it's really good (OFG3).

Because [rural health services] have been so good to [de-facto] I'm asked to go, occasionally I'll go, I like to do my own thing. But I'm going to the Valentines lunch at [location] to raise money it's a good reason to go... they go all out... the hall is packed (OFG3).

The research community valued the importance of friendship and the opportunity that *community* provides for physical, psychological, and social health and wellbeing.

There was a diverse range of hobbies enjoyed as personal and *community* activities. A hobby expands quality of life physically, psychologically, and socially. A hobby is a choice, a demonstration of a skill, which provides personal and *community* satisfaction. Following emergent interview and group meeting conversations regarding lifestyle modification programs, descriptions of enjoying individual hobbies emerged:

Photos, I sit and play card games to relax, and think, plan ahead (CH19).

I do a lots of crossword puzzles ... read constantly I read far too much ... I just devour books and the same with crossword puzzles (CH 20).

I have written books. Writing for me has been a stress release. My books were my release. It's important to me if I can't write I'm stressed ... frequently early mornings. Or middle night to get out the anger and stress (CH23).

I'm trying to do some knitting and paper work (O1).

I like reading books any sort except Sci Fi. I really like books when I get stuck in, I'm slow, I read every word. To read the paper ... it will take me more than a day, I read every word, I like that (O2).

as did hobby as a member of a *community*:

Member of Men's Shed (CHFG1).

Play cards, craft, bingo, mind games .... It makes your mind work I prefer that to bingo (CHFG1).

I've always been with junior farmers and junior chamber of commerce, I was the first female member of [the state] ... I've always done things for the community minded and brought up in the country you played sport and you belong to golf clubs and things like that in the community (OFG1).

I play scrabble one afternoon a week we go to the community centre here in town there's about four, well anything from two to six, social we help each other play it's not competitive, just something different to do (OFG1).

The Get Active Program, walking group, gardening lawns, walk daily. Old exercise videos. (LFG1)

The research community also considered voluntary work a hobby:

I'm a councillor on the [location] Council (CHFG1).

I use the PC down there [history room]. I catalogue the articles in the history room so the PC is really good for that search and find information for that. Photograph things and load them up on the PC that keeps me busy one afternoon a week (OFG1).

I volunteer because I'm positive and like to be active, I run the bus for the old people (CHFG1).

Partners were sensitive to the opinions and judgement made by their local *community* and if they chose to engage with alternative communities:

I try to participate as much as I can, for the company, I don't find that in [local community] ... so I pull back, I go over to [other community] (CH14).

People living with CCCs can intentionally or unintentionally drift into isolation. Time, energy, and concentration are needed to sustain friendship; opportunity and hobbies require huge efforts on their part.

The data were indexed to three labels; friendship, opportunity, and hobby, which were charted to *community*. This offered understanding of *community* influences and the effect of personal choice on physical, psychological, and social quality of life, which provided personal and *community* support and value. *Community* charted the research community as living and sharing comparable situations with similar characteristics: the everyday actions partners take, the people they choose to spend time with, and the principles they choose to defend and define. *Community* can impact *personal health*, *family*, *lifestyle*, use of *computers*, and experience of and engagement with *MyHR* as a concept, which may maintain, expand, or require re-creating **self-identity**.

#### 4.3.1.5 Computer

The category *computer* describes an electronic device that can process, send, and receive information to complete a series of tasks and to produce information. Linking the categories shows that for a person living with CCCs in a rural community, *computer* has potential, qualities, and limitations. *Computer* use and utility can impact, positively or negatively, on *personal health, family, lifestyle, community*, and experiences of and engagement with *MyHR*.

During interviews and group meetings in each phase of data collection the partners narrated information freely that allowed expression of their needs and understanding and was used to index to five labels, which were charted to *computer*, and mapped to the theme **self-identity**. These are presented in Table 25, which links them to the research objectives and provides a brief description of each label, category, and theme. A research perspective and an example of narrative follow.

**Table 25. Computer**

	THEME	Description
	<b>SELF-IDENTITY</b>	Understanding and belonging, which positively or negatively affects and effects physical, psychological and social health and wellbeing
	<i>Category</i>	
	<i>Computer</i>	<i>A medium for contact, a personal memory, personal information, impacts our perceptions</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.2.3	<u>Contact</u>	Online identity; computer mediated; connected
Ro1.2.3	<u>Computers are</u>	Partners provide their personal description
Ro1.2.3	<u>Personal use</u>	Creative, volunteering, personal, professional
Ro1.2.3	<u>Family use</u>	The way in which research partners describe family interactions and use of a computer
Ro1.2.3	<u>Effect of CCCs on computer use</u>	The positive or negative effect suffering from CCCs has on the use or non-use of a computer

Contact indexed the types of communication between friends, family, and communities through *computer*:

I'm a home educator that's basically my life ... There's other parents I get together with on the computer (CH1).

I do craft things, order a lot of materials and things like that for the craft room, I shop a lot on the computer, I do banking, emails. Actually I don't use Skype, I've got it but I don't actually

use it but I think I should start because I mean the kids are away from home and I think it would be easier. I am on Facebook (CH6).

I don't send mail any more, well I do but it's electronic mail and I can get a response immediately (CH11).

Great to keep in touch, a lot of knowledge, I use social media, birthdays, relaxation. Chat to relatives, emails in general. I get good information as well (L1).

[I] get on there at eight in the morning and then studying and reading and things (O4).

*Computer* is a resource for contact: communication, education, recreation, and financial management.

Early in the data collection, an emergent question was, 'what do you think about computers?' The responses were indexed to computers are and charted to the value of *computers*, equally recognising that there are other ways of obtaining information. There was a basic awareness and understanding of *computers*; their limitations, and the importance of also having other interests; positive responses were concluded with self-conflicting comments:

[The] computer is a tool, yes a concise way of putting information and retrieving information .... but there are other ways of doing it (O4).

Computers are brilliant ... the best computer is between our ears. Too many people are relying on computers to do things. There is a lot of truth in the maxim use it or lose it (CH28).

Very fine things. Most necessary thing invented ... no electric no computer (CH16).

Great to keep in touch ... can be scary. It's a good and bad thing (L1).

With the same question, some responses differed but were also self-conflicting:

[I'm] totally unaware of the computers ... I think they just scare me, I think it's just lack of practice. I can type on one I have used one. I did a book for Tafe .... I have got a mobile phone, I use it when I travel to the mainland so I ring or text and say ... (CH20).

Some acknowledged awareness and use of *computer* but did not attribute any value to these. The reason provided for reluctance and limited skills:

A waste of time. Because people believe everything in there. You can vegetate on it. I have looked at couple of thing on it. It didn't help me at all (O2).

However, in a later phase of data collection they offered a different view:

I'll have a word to him [GP] about it [MyHR] and see what he says. He's always playing on it [the computer] so I'll ask him what's the next deal and I'll put some more info on it [MyHR]. I haven't written the day I stopped smoking in there yet. I'll put it on because I've got to catch up with a lot of things, about 4 weeks of stuff; it only takes a little while to punch the numbers. I should of thought about adding the smoking thing; I'll get that in (O2).

The researcher recorded a journal note at the time 'will an essential component to MyHR be a reminder to add data?'

Computers are essential for some, a necessary evil for others, and for others are unnecessary. However, with time, support, and inclusion, a purpose for computers can be identified in the research community.

Personal use and family use were indexed from the question 'what do or would you use a computer for?' and charted to the category *computer*. Personal use was indexed from responses that included social networking, recreation, voluntary work, education, emotional and physical health, work, and bookkeeping:

All day everything, email, social, banking, education (O3).

I met [wife] online (CH19).

It's good for my mind and coordination (O1).

[R]esearch, data collection, data management, education (CH11).

I volunteer at the online centre (CH28).

Personal use and engagement with *computers* were also recognised as a linkage to *lifestyle*: social networking, recreation, voluntary work, education, cognitive and emotional health, work, and financial management.

Family use was indexed from:

We use them [computers] daily. Everybody from probably the age of two upward, well [son] is five now and he's been using it for a least two or three years [for] home education (CH1).

I've taught [husband] and my parents in their 80's to use them. It's exciting. My Dad loves to sing so he can look up the lyrics, look at photos... (CH 13).

All family members have a computer each (L1).

[W]e've only got one computer [son] gets on there at eight in the morning and then he's studying and reading and things. I'm a bit jittery and then when I go and do something I hit the wrong keys. So I need a bit of help from [son]. We don't use the computer all the time so we need help from [son] (O1).



A *computer* was viewed as integral to family use. A *computer* allows the partners and *family* to seek out information and support and to connect with others for education or recreation purposes.

The effect of CCCs on computer use and the effect of computers on their CCCs elicited varied and conflicting responses:

I have difficulty concentrating I find it really hard. I can muck things up quite a bit. I press the wrong buttons with my [CCCs] and press a couple of times (O1).

including personally conflicting responses:

I play games, it's good for my mind and coordination. I communicate with my nieces on Facebook all the time (O1).

and conflicting responses between partners:

[My husband] and I had separation anxiety after [family bereavement experience] ... With this [iPad] I could go out into the paddock and continue (CH13).

[T]hey [the hospital] asked me to use the [POCT] to upload my [CCCs] information (CH1).

The data about the effect of CCCs on computer use and the effect of computers on their CCCs, which indexed various self-conflicting and group-conflicting responses, require consideration. For people living with CCCs, the use and utility of *computers* can change their healthcare provision experience and engagement and the way CCCs are communicated via *MyHR*.

The data indexed to five labels: contact, computers are, personal use, family use, and effect of CCCs on computer use, which charted to *computer*. This offers understanding of the use and utility of *computers* and their influences. *Computer* charted as a medium for contact: a personal memory and a source of personal information, which may impact on perceptions. *Computer* recognises the basic personal and *community* awareness and understanding of *computers*, the limitations and importance of ensuring there are alternative *lifestyle* interests and alternate *computer* communities to provide a connection with others, and the ability to seek out information. *Computer* can reinforce *community*; experiences can be acknowledged and confirmed by others, leading to sharing and learning of new ways to survive living with CCCs. *Computer* allows *community* involvement at a personal pace and reduces isolation by enabling otherwise difficult-to-access social networks.

Computer impacts on *personal health, family, lifestyle, community* and the experience of and engagement with *MyHR*, which may maintain, expand, or require re-creating **self-identity**.

#### 4.3.1.6 MyHR

The category *MyHR* describes an opportunity for equitable, person-centred, integrated digital exchange of healthcare information and healthcare provision. Linking the categories shows the potential, qualities, and limitations of *MyHR* for *personal health, family, lifestyle, community*, and *computer use and utility*.

During each phase of data collection, interviews and group meetings provided an opportunity for partners to express their needs, understanding, experiences of and engagement with *MyHR*. Analysis indexed the data to six labels, which were charted to *MyHR* and mapped to the theme **self-identity**. These are presented in Table 26, which links them to the research objectives and provides a brief description of each label, category and theme. A research perspective and an example of narrative follow.

**Table 26. MyHR**

	THEME	Description
	<b>SELF-IDENTITY</b>	Understanding and belonging, which positively or negatively affect and effect physical, psychological and social health and wellbeing
	<i>Category</i>	
	<i>MyHR</i>	<i>Equity, informed choice, acknowledged, involved, encouraged, opportunity for an exchange of health information</i>
	<u>Label</u>	
Ro1.2.3	<u>Consumer focus</u>	The ability to incorporate personality in the design
Ro1.2.3	<u>Family/friend/community registration</u>	Inclusive, sharing, awareness, value of information
Ro1.3	<u>Timeliness and availability</u>	Important to self-identity
Ro1.2.3	<u>Personal use and utility</u>	Self-management
Ro1.3	<u>Change with MyHR use</u>	Changed individual and community perceptions of computer use and the value of their contribution to their health management through electronic communication
Ro1.3	<u>Responsibility</u>	Personal and professional accountability and responsibility

Consumer focus confirmed that people living with CCCs require information, acknowledgement, and involvement. Further, the research community believe that given the opportunity, they could lead change:

[E]ncourage consumers and ensure they're informed (CH11).

[T]hey haven't thought about it very much from the personal consumer point of view and really that's the most important thing ... what does the customer need and then you take it from there (CHFG1).

[I]f you want to know how anything is going to work you give it to the users (CH13).

[T]hey should really know consumers can encourage the professionals (CH14).

One partner expressed a potential financial concern:

It doesn't seem like it'll hit me in the pocket (O2).

A journal note recorded at the time: 'no other partner or group has expressed this concern, should I have asked or talked about it?'

Consumer focus requires open information, acknowledgement, and involvement. The research community believe that given the opportunity they could lead change. One partner raised a financial implication of MyHR, which was not a question considered or asked during data collection. However, it should be acknowledged that this partner might have verbalised a thought common to many. Any implementation of regional/national/international proportions should consider all consumer concerns (Homko et al. 2008).

Family/friend/community registration was indexed from interviews and the group meeting enquiry 'have you told anyone or shared any information regarding [MyHR]?' Some partners have assumed the role of 'MyHR carer' within the family. Earlier in the data collection they identified as carer for their fathers, while during this discussion they assumed a broader role, a 'MyHR caring' role for their husband. They went further and assumed that their daughter will take on the 'MyHR carer' role. Within the role of the carer, they identify a role for *MyHR*:

I've talked about it [MyHR] with my husband and my dad and they seem quite happy for me to do one for them ... My daughter could do it she's always on the computer. She can always know about Dad's stuff (CH 6).

There is opportunity for *MyHR* to form a central part of family healthcare provision. There is an awareness of responsibility within the family to engage:

[M]y husband has signed up as well but I don't know how far he has got with it (LFG2).

I talked to my son in [major city] about it...he has two kids he has looked it up to start recording things (CH 12).

I've spoken to them about it [MyHR] ... My son, his daughter is a really good example of where it would be really useful to have her history in one place because she been to the children's hospital in [major city] so many times, check-up, here and there and if anything goes wrong it still all needs referring to because she's had a lot of severe [health] problems (O4).

Family/friend/community registration highlighted improved healthcare communication between siblings acting as informal carers and healthcare providers and professional carers:

Yes my friends ... how useful it would be for them, they have [CCCs] and their sister has [CCCs] the family rotate care, carers rotate ... they're all computer savvy, and they can document there ... [I can see] how the family and health professionals could benefit from it (CH23).

My son ... has just been diagnosed with [a genetic illness] he has a new Dr it would be great if he could access all his old blood results without requesting (O4).

Family/friend/community registration identified *MyHR* as part of the carer role within their family and community. There is an opportunity for *MyHR* to form part of a central family value, a family responsibility. Friends highlight the potential for improved healthcare provision, communication between siblings as informal carers, and healthcare professionals as carers. *MyHR* requires a critical mass for its benefit to be realised. Engagement is needed not only at national level but also at regional, local community, and personal levels. Support and information should be accessible to all stakeholders.

Engagement requires the availability of current information for all concerned. The research community highlighted the logical reason for *MyHR* as timeliness and availability of healthcare information exchange and healthcare provision:

Timeliness, I agree the exchange of information (CHFG2).

It's so obvious you wonder why it's not there already. The availability will be great (OFG2).

[T]his is a [CCCs] journey which would be relevant, all the information should be available it should all link; x-rays, physio, Dr and myself should use it (CHFG2).

I spoke to the nurse she said my cholesterol was fine then I spoke to someone else and they said it was high but last time the Dr explained the good cholesterol and the bad cholesterol and that's what I wanted to check. So now I have to ring back and get a break down of the two cholesterol, whereas if I had it in there [MyHR] I could see them [the results] (LFG2).

Personal use and utility of MyHR is clearly narrated:

Newborn registration would make sense, all the forms are on [MyHR] (CHFG2).

Allergies are very, very important. The emergency access is vital and really needed I think it's a good thing (CHFG2).

[S]ometimes I have had to be treated by doctors' interstate for [CCCs], I'm very sick before they do anything. I'd like it if they knew what the treatment was now, because usually I have to go straight to hospital (CH12).

I think it's a great idea much better to have it recorded in one place (OFG4).

However, some presented as cautious about the personal use and utility of *MyHR*. They recognise the relevance of the personal use and utility of *MyHR* for travel purposes, but had reservations regarding the benefit for local communication of their CCCs:

I can see the benefit more so if you were travelling, I guess it would be also of benefit me saying to the GP about it. I think it's a good thing and perhaps more relevant to people who travel because it would be a marvellous tool (LFG2)

They demonstrated reservations, wanting to hear everybody else's responses:

I think it's good, I will see how it goes over the year and see how much it's used by everybody (LFG2).

Personal use and utility indexed the personal, preventative, acute and CCCs use and utility of *MyHR*. Some partners stated that they saw less relevance for *MyHR* at a local level and demonstrated a level of caution, wanting to see how *MyHR* develops in the community before engaging. Others may only engage with *MyHR* when they perceive the necessity.

Those partners who during phase one data collection narrated a reluctance to use a personal computer changed their perception of computers during data collection phases two and three. After registering and engagement with *MyHR*, the partners who attended different group meetings demonstrated that perception of computer changes with MyHR use:

If I go to a specialist in [town] he can tap in to it... it should be there at their fingertips. Professionals seeing me have to use it ... all health professionals in the community will be linked and communicate that's a lovely idea (CH21).

[P]ut it all on there [MyHR] and then I've got an easy reference for the Dr or whoever (O2).

Responsibility indexed comments from those who had communicated to their healthcare providers their wish to share healthcare provision via *MyHR*. All had received negative responses and felt that their enquiry was treated dismissively:

[The Dr] was claiming things that were funny, how can he be responsible for what I add? I can't see how he's responsible (CH 12).

I spoke about it they've got the interest, but you know Drs are lazy, they are that's what I think it is you know .... You know what they say, 'too time consuming, how long do you think we have with each patient?' ... people make it a lot, they're not willing to listen a little bit further you know (CH14).

I'm not in a position to tell my GP to get involved, I have asked, made inquiries, declared my interest (CH13).

I know it's my record but that was [theirs], and it was [their] point of view and [their] choice, but nothing more has happened since then (O3).

*MyHR* should be viewed as a joint responsibility of healthcare providers and the healthcare user, not the sole responsibility of one or the other.

The data were indexed to six labels: consumer focus, family/friend/community registration, timeliness and availability, personal use and utility, change with MyHR use, and responsibility, charted to *MyHR*. *MyHR* charted to the opportunity for an informed, acknowledged, involved, encouraged, equitable exchange of health information. *MyHR* charted as relevant for experience of and engagement with *MyHR*.

All partners experienced and engaged with *MyHR* and demonstrated its value for *personal health*, *family*, and *community*. Those who felt *MyHR* to be easy to use engaged *personal health* and supported their *family* and *community*. They were able to demonstrate their need for *computers* and *MyHR* and to accept the concept. *Community* influence affected their experience of and engagement with *MyHR* and supplemented interactions with *family* and *lifestyle*. The category *MyHR* as a dynamic concept provided understanding and a requirement for the research community to be valued, informed, and involved in all healthcare decisions, which could be maintained, expanded, or require re-creating **self-identity**.

#### 4.3.2 Summary self-identity

The theme **self-identity** was mapped from the categories *personal health, family, lifestyle, community, computer* and *MyHR*. This section has provided examples of the analysis of the research community's need for understanding and belonging, which positively and negatively affects and effects their physical, psychological, and social health and wellbeing. Acknowledging the research community's understanding of their healthcare requirements and realising their experience of and engagement with MyHR ensured that **self-identity** linked to the themes **knowledge** and **access**, and to the overall research objectives presented in section 1.2.2.

**Self-identity** demonstrates how a person living with CCCs understands, communicates, and engages with their transitional health requirements and experiences their environments and their social relationships. **Self-identity** recognises and values the potential, qualities, and importance of physical, psychological, and social health and wellbeing for a person living with CCCs. What may appear insignificant everyday contacts and choices affect and effect **self-identity**. **Self-identity** values dynamics, experiences, opportunities, and consequences, the culture in which a person is born and develops, the desire to belong and feel connected. **Self-identity** is a personal journey: a person's way of life, interests, opinions, and behaviours, and where and how they live shapes their **self-identity**. **Self-identity** also exists within a group of people living and sharing similar situations with similar characteristics: the everyday actions taken, the people they choose to spend time with and the principles they choose to defend and define. **Self-identity** supports awareness and understanding of the limitations and importance of engaging in alternative interests, communities, and the ability to seek out information. Experience and skills are acknowledged and confirmed by others, allowing sharing and learning of new ways to live with CCCs.

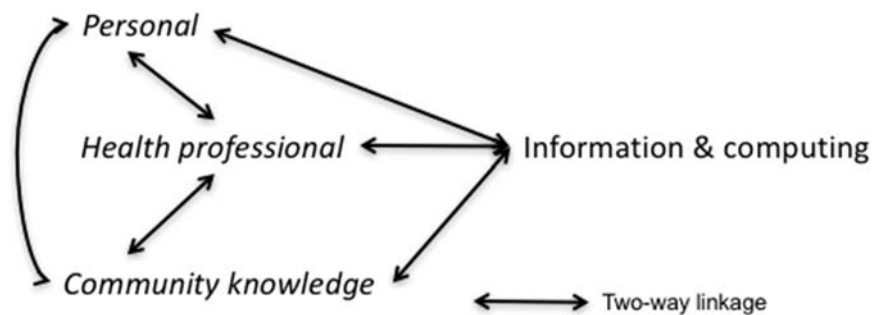
**Self-identity** may be maintained, expanded or require re-creation because of how the transitions encountered by a person living with CCCs in their everyday actions and environments positively or negatively affect and effect their desire to belong and feel connected, who they know themselves to be and how they recognise how they belong, their way of life and values, the people they choose to spend time with, how they choose to interact with people and information, and the principles they choose to defend, define **self-identity**.

### 4.3.3 Knowledge

THEME	Description
<b>Knowledge</b>	Familiarity, knowing, awareness or capability with or of something or someone gained through experience and education

**Knowledge** mapped shared and built on experiences and education. In the context of this research it is described as familiarity, knowing, awareness, appreciation of information, events and ideas.

The theme **knowledge** was mapped from four categories, *information & computing*, *community knowledge*, *health professional*, and *personal*. Each of the categories correlates and they collectively mapped to **knowledge**; the linkages are represented in Figure 14. A brief description of the individual categories and labels they were charted from follows. An in-depth description is provided in the subsequent sections as the labels are charted to categories and mapped to themes.



**Figure 14. Knowledge category linkages**

Through *personal* and *community knowledge*, experience and knowing and the discussions of *information & computing* and *health professional*, there was increased awareness and enriched experience of and engagement with MyHR. *Health professional* identifies the challenges, opportunities and consequences for *personal* and *community knowledge* created by living with CCCs and *information & computing*. *Community knowledge* values the sharing of *personal* capabilities and skills, which may benefit the experience of and engagement by *health professionals* with CCCs and *information & computing* transitions. Equally, *health professionals* need increased *information & computing* competencies and engagement to value and support the capabilities and experiences of *community knowledge* and *personal*. *Information & computing* identifies strengths, weaknesses, opportunities and threats for *personal*, *community knowledge*, and *health professional*.



### 4.3.3.1 Information & computing

*Information & computing* describes the ability to digitally search for, receive, or send relevant information to advance *personal* and *community knowledge* and healthcare provision. Linking the categories *community knowledge* and *personal* experiences and engagement revealed that *information & computing* and the experience of using MyHR as a dynamic concept led to increased opportunities for MyHR engagement, changed the perception of *information & computing*, and drew attention to the commitment required by *health professionals*.

During each phase of data collection, the interviews and group meetings provided the partners with the opportunity to express their understanding, skills, use and utility of ICT. Analysis indexed the data to three labels, charted to *information & computing* and mapped to the theme **knowledge**. These are presented in Table 27, which links them to the research objectives and provides a brief description of each label, category, and theme. A research perspective and an example of narrative follow.

**Table 27. Information & computing**

	THEME	Description
	<b>KNOWLEDGE</b>	Familiarity, awareness or capability with or of something or someone gained through experience and education
	<i>Category</i>	
	<i>Information &amp; computing</i>	<i>A way in which individuals actively or passively give or receive information electronically</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.2.3	<u>Personal, professional and society changes</u>	The changes that have occurred over time because of the use of computers to give or receive information and therefore knowledge
Ro1.3	<u>Personal and professional use and value</u>	The value given to the ability to access information and increase knowledge through the use of a computer
R01.3	<u>Practical application</u>	How the computer is used personally or within the community

The partners narrated their familiarity and capability with *information & computing*, in either or both a personal or professional capacity. Personal, professional and society changes indexed how *information & computing* awareness has made a significant impact on their personal and professional life, espousing the belief that this is a society change:

I used to sit with one of these little calculators to do a sum. I would punch in numbers one after the other, computers have just revolutionised that, my life in the work place. They changed my life and change society dramatically over the last 30 years (CH11).

There were a diverse and contradictory range of opinions indexed to personal and professional use and value. These acknowledge the impact *information & computing* technology has on whether partners use it or not. *Information & computing* is described as a requirement for communication and learning. Equally, there is an awareness of the weakness of computing and connectivity:

[G]ood or pain in neck, I have used them for years when I left work I needed a break from them. [Now] I use them for writing, emails, networking, typing, creating cards from photos (CH23).

Great to keep in touch, a lot of knowledge. Social media can be concerning (L1).

Practical application indexed the consideration of practical, realistic, and rational use of *information & computing*. The community shared their opinion of personal use and the utility of *information & computing*:

[The] computer is a tool yes a concise way of putting information and retrieving information .... [I] go down to the history room ... I catalogue the articles in the history room so the PC is really good for that. I search and find information for that. Photograph things and load them up on the PC that keeps me busy (O4).

For the research community, availability of and interaction with computers, the internet, and MyHR means a practical method for addition of and to detailed information about their past and current health. This can inform their current and future health choices:

[R]eferred to physio and chiro, crossing paths and catching up. If they added to the [MyHR] it would be far less hit and miss... (CHFG2).

The data indexed to three labels: personal, professional and society changes, personal and professional use and value, and practical application, charted to *information & computing*. *Information & computing* charted diverse emotions ranging from enthusiastic and life-changing through to negative or opposing. The experiences of and opinions on these positive and or negative effects indicated practical real-world attitudes toward *information & computing*. Use and utility of *information & computing* requires *personal*, *health professional*, and *community knowledge* awareness, capability, and experience. The category *information & computing* provides insight into the partners' requirement to be exposed, informed, supported, and involved in *information & computing* activities that may maintain, challenge, or expand **knowledge**.

### 4.3.3.2 Community knowledge

*Community knowledge* describes a supportive environment that values cooperative, inclusive, engaging behaviour. *Community knowledge* is a means of exchanging ideas, information, and networking, which reveals diversity and promotes participation. Linking the categories and *personal, information & computing* and *health professional* mapped the partners' increased awareness and demonstrated an enriched experience of and engagement with MyHR:

[U]sually within a community people talk, so if one person is convinced it's the right way to go they'll convince others and through experience you'll grow (CH14).

During interviews and group meetings in phase three of the data collection, the research community were asked to reflect on how and why they may have benefitted from the research. Analysis indexed the data to three labels, charted to *community knowledge*, and mapped to the theme **knowledge**. These are presented in Table 28, which links them to the research objectives and provides a brief description of each label, category, and theme. A research perspective and an example of narrative follow.

**Table 28. Community**

	THEME	Description
	<b>KNOWLEDGE</b>	Familiarity, awareness or capability with or of something or someone gained through experience and education
	<i>Category</i>	
	<i>Community knowledge</i>	<i>Social learning; empowerment; enabling; awareness; communication</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.2.3	<u>Community benefits from research</u>	Experience, information, understanding improvement, opportunity, connection, support, change, engagement, familiarity
Ro1.2.3	<u>Research benefits from community</u>	Feedback, opportunity, learning together, real-world community views
Ro1.2.3	<u>Community role for MyHR</u>	Raising awareness, support

Community benefits from research labelled the input of and connection with the research experience, information, and support that has provided an opportunity to engage with the information on a personal level and share in *community knowledge*. Community benefits from research indexed:

[K]nowledge lots of people didn't know about it [MyHR] before ... (CH1).

[T]he value [is] you're listening to a lot of people's opinions. I think you know with any undertaking as a whole, community benefits more than just one person speaking out .... You have to speak to the people so these community, what do you call them, workshops, where you ask the questions, then you'll get the feedback that's required and bring about change. (CHFG3).

This is an opportunity for ourselves working as a community to bring our comments and skills together and provide structured research feedback and hopefully bring about change. (OFG3).

This is also evident from the researcher's journal notes recorded at the time:

There was a different level of communication and commitment. The familiarity at groups meetings demonstrated, an understanding of each other, there was a lot more free talk and open discussion. The groups talked as a research community, thinking about their health and healthcare provision in a different way. The research has provided a focal point.

When the research community identified with their research, they recognised the value of community participation and the empowering change it made to all partners.

Research benefits from community provides evidence and further validates the philosophy, CBPR principles, and research design:

I know from teaching, it's exciting at the beginning, start from where they are with lots of feedback and opportunities for reflection sort of things...I think this research is great, everybody likes to be involved and feel they have an opportunity to give to....We're starting and learning together the same as learning computer together you share so much (CHFG3).

[T]his is good we've all got different skills and different attitudes ...I have my own views and I respect everybody else's views (CHFG3).

[I]f you're consulted you have the actual point of view rather than the perceived point of view. .... I agree, I think so with any research then at least you've had your input, an opportunity (LFG3).

You need as much info as possible I think getting a story is getting as much information as possible. By asking a question you're getting the information on those lines ...I think the community is very underestimated by people doing research...there is a lot of good brains out there (OFG3).

Research benefits from community provided personally and contextually significant, feedback, opportunity, learning together, community skill and views, which value and justify personal and community commitment, participation and provision toward better research outcomes.

Community role for the MyHR was indexed from reflection of experience of and engagement with MyHR. The research community respects that this may be contradictory to the opinions of a wider community:

I think a lot of my hippy friends will see it [MyHR] as big brotherish, rather than helpful ...  
For me, now I don't have to apply to big brother to look at my [MyHR]. That's good. I'm all  
for knowing stuff it makes it easier (CH1).

MyHR requires critical mass to be effective. The research community valued the support provided during the research. The narratives provide evidence of the usefulness of community facilitation in the implementation of MyHR:

How many have got on [MyHR] because of this research? People need help with it (CH11).

I just think an important part of the whole process will be having help (CH12).

More people I'm sure would adopt it [MyHR]. Consumers can encourage the professionals about it [MyHR], they'll see there is a demand for it [MyHR] ...it [facilitation] increases their awareness (CH14).

The data indexed three labels: community benefits from research, research benefits from community, and community role for MyHR, charted to *community knowledge*. *Community knowledge* charted a supportive, cooperative, inclusive, and engaging environment. It encouraged networking opportunities and an exchange of skills and information that valued and promoted community participation. *Community knowledge* requires *personal* engagement and participation to assist proactively increased awareness and changed attitudes toward *information & computing* and *health professional*. The category *community knowledge* provided insight into the value of being exposed, informed, and involved in *community knowledge* activities to maintain, challenge, or expand **knowledge**.

#### ***4.3.3.3 Health professional***

*Health professional* describes skills competencies, awareness and responsibility. The research community are respected and acknowledged as having unique experiences of their health. For all health professionals, the transition from delivering paternalistic, siloed healthcare provision via an EMR or EHR, as described in section 2.4.2, to connecting with quality healthcare provision via MyHR, should present an opportunity to build their experience of engagement with a contemporary collaborative approach to healthcare provision. Further, this approach should

acknowledge the unique experiences of the person living with CCCs, and respect the relationship by including and involving, listening and providing honest communication, considering their needs and preferences, and advocating for the person's rights.

Linking the category *health professional* identified *personal* and *community* challenges, opportunities, and consequences created by living with CCCs and *information & computing*. *Community* recognises that sharing *personal* capabilities and skills may benefit *health professional* experiences and engagement with transitions in CCCs and *information & computing*. Equally, *health professionals* need increased *information & computing* competencies and engagement to support *community* and *personal* capabilities and experience.

At interviews and group meetings during each phase of data collection, the partners expressed their opinion and experiences of the health professionals involved in their healthcare provision. Analysis indexed these data to three labels, charted to *health professional* and mapped to the theme **knowledge**, familiarity, and awareness or capability with or of something or someone gained through experience and education. These are presented in Table 29, which links them to the research objectives and provides a brief description of each label, category and theme. A research perspective and an example of narrative follow.

**Table 29. Health professional**

	THEME	Description
	<b>KNOWLEDGE</b>	Familiarity, awareness or capability with or of something or someone gained through experience and education
	<i>Category</i>	
	<i>Health professional</i>	<i>Skills, within context, competencies; awareness; responsibility</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.3	<u>Healthcare professional comprehension of MyHR</u>	None, poor, outdated, inadequate
Ro1.3	<u>GP comprehension of MyHR</u>	Reactive, negative, objection, biased, poor practice, unaware, outdated, limited capacity
Ro3	<u>Interaction</u>	Interaction, history, one record, information

Healthcare professional comprehension of MyHR was indexed from experiences of the role of the health professionals involved in the partners' healthcare provision and how MyHR can be applied. As highlighted in section 4.2, Table 19, each partner required regular contact with more than four different healthcare providers. All the healthcare professionals spoken to by a partner were aware of MyHR, but all responded with reasons as to why they did not use MyHR; a lack of healthcare professional comprehension of MyHR was not verbally disclosed:

[I] see a few Drs, I was getting a CAT scan and then an MRI ... and I asked ... the MRI [staff] were happy to put it on my eHealth thing. But they were under instruction to send it to the Dr and the Dr who ordered it, anyway and he doesn't do eHealth ... that was a urologist, and I've talked to the locum GP and he doesn't like it either, he used a different excuse to GP. GP used another excuse ... then I talked about it to [the other] locum GP... he talked about bees a lot but not eHealth very much. So yes I haven't found any Drs that do that yet and I haven't been to any other Drs, but the MRI people ... they were happy to do it (CH12).

For all healthcare professionals, transitioning to MyHR would allow insight into the complete and unique experiences of living with CCCs, to build on their CCCs competencies and deliver a greater level of person-centred quality healthcare. A core competency of any health professional is communication. In contemporary healthcare provision, comprehension of ICT is fundamental for appropriate transitional complex healthcare provision. In Australia, healthcare professional comprehension of MyHR should not be regarded as a choice, but as an adjunct to the delivery of all healthcare provision. This research has identified a gap in competencies, i.e., poor healthcare professional comprehension of MyHR. This gap in competency delays the acceptance of a digital communication resource readily

available to all healthcare practitioners registered with the Australian Health Practitioner Regulation Agency (AHPRA):

Child Health Nurses are not using it. I mentioned it [MyHR], they have their own paper base. They only use the computer for appointments (CH1).

Hand physio ... just looked blank (CHFG2).

I tried to get my Drs involved, I tried to get my specialist ... I gave them access when I went down for my appointment and [they] basically, well I talked to [them] about it. [They were] saying [they] didn't like the fact that other doctors could see basically or other individuals could see. If my other Dr had what was it, access, then he could see my [CCCs] stuff and stuff like that. It wasn't a problem to me but it's a problem to [them]. I know it's my record but that was [them] and it was [their] point of view and [their] choice ... (O3).

GP comprehension of MyHR was identified when the partners approached the topic during GP consultation:

My GP doesn't use it and [GP] reaction was it's better to spend the money on software development between different health professionals. He said there's no point ... He says it [MyHR] doesn't have a shared ... that's what this is though? (CH13).

GP needs to understand what his objection is ... has he dealt with that yet? (CHFG2).

I don't know what his particular bias is or whether he doesn't want to be bothered? He doesn't see. And the one in [the city] still writes all their accounts out by hand she doesn't want to embrace it at all (CH13).

I guess the long-term view on this it might expose their inadequacies with computer skills. (CH28).

Well my GP writes on a computer [practice] why does she not have MyHR? (L2).

[A]re family GPs aware of this service of MyHR? (OFG2)

GPs need to engage with and extend their comprehension of and competency in MyHR, rather than avoiding engagement with MyHR.

There is a need for action and interaction:

The bit that's needed is the interaction from the Drs with the GPs. My son, his daughter is a really good example of where it would be really useful ... if anything goes wrong it still all needs referring to because she's had a lot of severe [CCCs] (OFG3).

[I]f ever I have to go to the doctors, with all that's wrong with me from years ago, which I may not remember, it's there in [MyHR] because in our situation we've only known each other for 10 yrs. So it's all blank before that so we need our shared record from earlier on it, for anyone who needs to know (CHFG3).



If a person living with CCCs is not in a position to access or engage with MyHR, all healthcare providers should at the very minimum have the skills and ability to interact through one person's health record about one person's health:

If I go to a specialist in [town] he can tap in to it, because when I went down for my last [CCCs] exam it wasn't in ... Most of it should be there at their fingertips if it is put into the system and the system works. Professionals seeing me have to use it (CH21).

The data indexed three labels: health professional comprehension of MyHR, GP comprehension of MyHR, and interaction, charted to *health professional*. *Health professional* charted a need for healthcare provision to recognise, value, and support the unique understanding and attributes of people living with CCCs. *Health professional information & computing* skills and abilities impact *community knowledge* and *personal* engagement in and experiences of their healthcare provision. Equally, *community knowledge* and *personal* believe that their *information & computing* experiences and attitudes can effect *health professional* engagement in their healthcare provision. The category *health professional* provides insight into *community knowledge* and the *personal* opinions about *health professional information & computing* skills and application. There is a need for awareness, increased capability, and a responsibility to expand *health professional* competencies and **knowledge**.

#### 4.3.3.4 *Personal*

*Personal* describes information gained through involvement, observation, commitment, and factual knowledge. Linking the categories *personal* and *community knowledge* with exposure to and becoming familiar with *information & computing* and MyHR raises *health professional* awareness and understanding.

At interviews and group meetings during each phase of data collection, the partners provided data that was indexed to six labels, charted to the category *personal*, and mapped to the theme **knowledge**. These are presented in Table 30, which links them to the research objectives and provides a brief description of each label, category, and theme. A research perspective and an example of narrative follow.

**Table 30. Personal**

	THEME	Description
	<b>KNOWLEDGE</b>	Familiarity, awareness or capability with or of something or someone gained through experience and education
	<i>Category</i>	
	<i>Personal</i>	<i>Awareness and competence is acquired that requires exposure, participation and being familiar with something</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.2.3	<u>Literacy</u>	Varies, constantly changing (not only how well you can read and write but images and audio factors as well), a means to understand
Ro1.2.3	<u>eLiteracy</u>	The use of computers, the internet, videos, microwaves, audio players, mobile phones, spellcheckers. The knowledge and understanding of a computer and its uses
R01.2.3	<u>Health literacy</u>	The capacity to obtain, process and understand basic or extended health information; ensures participation; to have sufficient knowledge; responsibility
Ro1.2.3	<u>eHealth literacy</u>	Fundamental skills required to derive direct health benefits and engagement
Ro1.2.3	<u>MyHR literacy</u>	Fundamental skills required to derive direct health benefits and engagement within MyHR
Ro1.2.3	<u>Research</u>	Finding out about; goes beyond what we are told, it questions, and it's suspicious of the obvious; it looks for the hidden meaning

Literacy indexed a variety of responses: change, resistance, awkwardness, suspicion, something else to learn, understand or experience:

[W]e will all have to change but we don't often, we can't be bothered. We become more resistant as we get older (CH12).

It's a mind change ... I guarantee if I was back at work now I wouldn't even think about hand written notes (CH14).

I've never been very good at spelling ... and then I lose the other words I want (O1).

There is a need to consider literacy within the context of understanding resistance, awkwardness, and suspicion.

eLiteracy indexed diversity of acceptance, confidence, competence, and tolerance of digital technology, all of which provide opportunity to understand eLiteracy. There is a requirement for basic eLiteracy for effective engagement with MyHR:

How do people who know nothing about computers ask questions? Jargon is difficult ... 'codes' [are] more jargon (CH16).

[A]ll younger generation are tech savvy ... older people are tech savvy ... most people are aware of computers and their role ... they still scare me (CHFG2).

It's like accepting computers in the first place ... we panic more as we get older (CHFG3).

I did a business course last year. I wanted to know how to use it [a computer]. It annoys me when people reject them. It's a part of life now (LFG2).

[P]uzzle solving that's how I use and learn on the computer (OFG3).

[T]his is the age of computers so I taught myself ... I have circumvented problems; I am comfortable in most programs (CH28).

People living with CCCs indicate a level of health literacy. The research community understand that their CCCs are not curable; they require the opportunity to develop their understanding of the implications of this and be involved in their entire person-centred integrated complex healthcare. Health literacy requires personal and community understanding of CCCs diagnosis and their future implications and requirements:

[I]t doesn't need to be just Drs it's our bodies and our lives that this is all about and the two should be working together.... but that tends to get lost that's been my concern for a while...you're a number not a person (CH23).

[Y]ou might go away look it [health issues or medication] up on the PC and read all the possible side effects ... the person themselves needs to refer to the detail so they can remind the Dr if he has forgotten (O4).

If you want the best care, health professionals need to know your [CCCs] stories (CHFG2).

MyHR literacy indexed experiences during and following engagement with MyHR:

[I]t's amazing how you don't know how to breathe, no one ever tells you how to do it. It [correct breathing] does, it really does make a difference, it does ... I'm a very hard person to get motivated and I haven't been doing as much as I should. So writing it down in there [MyHR] does help ... I look at it [PC] and I think I should go and do that now (CH6).

I'll keep [personal] notes for now and match them with the Dr summary (LGFG2).

The main benefit will be that the health professionals can share information amongst themselves no matter where the patient is geographically (CH16).

I approve of it [MyHR] as means of being able to communicate ... with all the different health issues I've had (CH12). But it's [MyHR] yet another language I've been using computers since 1966 ... it's still another language to learn (CH12).

Those personally hesitant to enter information were happy for a family member to enter information into MyHR, recognising it as an easily accessible resource for themselves and healthcare providers:

[H]e [stepson] can put it all on there and then I've got an easy reference (O2).

The opportunity of communication of health information via MyHR was considered and valued, irrespective of physical or cognitive ability, as a form of health information sharing and integration:

I've ... entered some information on to it [MyHR] there is more that I will enter ...it's useful to remember what you've done (O4).

It's all very straight forward for me. To be able to access my record and add to it different medications etc. and reflect on my observations (CH14).

The more people who can add stuff in then I can get some benefit as well but also I need some time to actually put in notes (L1).

and a health awareness and monitoring facility:

I see this really relevant to people doing, blood sugars for example, you can record them all in one place; weight and blood pressure all that ... (OGFG2).

I can never remember, you go to a Dr and they say 'how many operations have you had' I could never remember and panic. So now I know they are all in the [MyHR] (CH6).

It's [MyHR] helped ... because I have had to look back over all my history to get it in there ... also some peace of mind that if there's an emergency there's some background in there (CH23).

My needs are basically simple ... the medication would explain what needs I have. You need to keep adding your own [history]. The history has to be available in emergency (CH1).

MyHR literacy requires motivation, understanding participation, monitoring, contribution, and integration of health information.

Research was indexed from reflection and understanding of some of the requirements for ongoing research, and how the research community think about MyHR as a national system rather than personally or as a community. There is recognition of MyHR as a contribution to ongoing research:

I can see it as being a huge data bank as well for medical researchers (CH12).

All this information could be of massive benefit and might find a cure having it down on the [MyHR] means collating information (CH28).

The data indexed to six labels: literacy, eLiteracy, health literacy, eHealth literacy, MyHR literacy and research, which charted to *personal*. *Personal* charted information gained through involvement, observation, commitment, and factual knowledge that is acquired following exposure to *information & computing*,

*community knowledge*, and engagement with MyHR. *Personal* was categorised from awareness, exposure, and understanding, what the partners know and their combined *community knowledge*, how they share their *information & computing* skills, and their experiences and engagement with *health professionals*. The category *personal* provides insight into *personal*, *community knowledge*, *health professional*, and *information & computing*; change management, participation, and literacy and eLiteracy requirements, to maintain, challenge, or expand **knowledge** of MyHR.

#### 4.3.4 Summary knowledge

The theme **knowledge** was mapped from *information & computing*, *community knowledge*, *health professional*, and *personal*. This section has provided analysis exemplars of **knowledge** as a diverse factor that positively and negatively affects or effects familiarity, knowing, awareness, and appreciation of information, events and ideas. Acknowledging the research community's readiness and capability to engage recognises and values individual and shared requirements and realises their experience of and engagement with MyHR. This ensured that **knowledge** links to the themes **self-identity** and **access**, and the overall research objectives displayed in section 1.2.2.

**Knowledge** requires awareness, exposure and capability, which may maintain, challenge or expand **knowledge**. **Knowledge** can be expanded in supportive, cooperative, inclusive, and engaging environments. **Knowledge** requires engagement and proactive participation to support increased awareness, become informed, and increase competencies and responsibility to change attitudes.

**Knowledge** is gained through observation or experience of a situation, condition, or object. **Knowledge** is exposure and appreciation, what a person knows and what their community knows, and how they share their expertise, experiences and engagement. **Knowledge** requires innovation and change-management skills, participation, and some literacy to maintain, challenge, or expand **knowledge**.

**Knowledge** can be maintained or expanded by the challenges, opportunities, and consequences created by living with CCCs. **Knowledge** is a fundamental requirement. Sharing unique **knowledge** can benefit others living with or without CCCs, and influence and improve healthcare experiences. Community exposure and

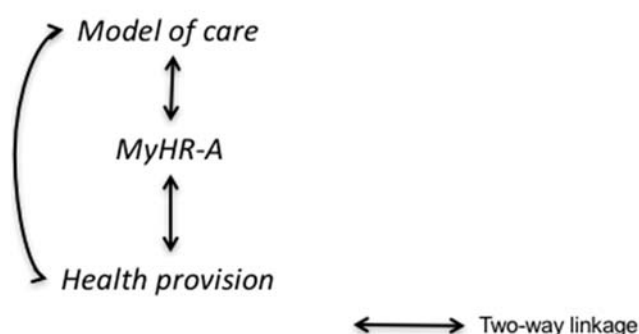
exchange of **knowledge** changes attitudes, endorses equitable engagement, promotes participation, and suggests proactive, practical, and rational approaches.

#### 4.3.5 Access

THEME	Description
Access	Connects, provides a flow of information between subjects and objects

**Access** mapped the research community and personal need for a connection. **Access** is described as a flow of information between families, community, and healthcare provision.

The theme **access** was mapped from three categories: *model of care*, *MyHR-A*, and *health provision*. All of these categories co-relate and were collectively mapped to the theme **access**. The linkages are represented in Figure 15. A brief description of the individual categories and labels from which they were charted follows. An in-depth description is provided in the subsequent sections as the labels are charted to categories and mapped to themes.



**Figure 15. Access category linkages**

*Model of care* can influence and determine the choice of *health provision* and the ability to experience and engage with *MyHR-A*. The experience of and engagement with *MyHR-A* can influence and determine the choice of *model of care* and *health provision*. *Health provision* can influence and determine the *model of care* and experience of and engagement with *MyHR-A*.

##### 4.3.5.1 Model of care

*Model of Care* describes how best to provide healthcare across the many specialty areas required to address the transitional complex care requirements of people and communities living with CCCs. By linking these categories, *model of care* should

support the evidence-based characteristics of practice required for *health provision* to a population at risk, to bring about changes in their experience of and engagement with *MyHR-A* and *health provision* that satisfy the individual and community requiring care.

At interviews and group meetings during phases two and three of data collection, the partners provided data that were indexed to four labels, charted to the category *model of care*, and mapped to the theme **access**. These are presented in Table 31, which links them to the research objectives and provides a brief description of each label, category and theme. A research perspective and an example of narrative follow.

**Table 31. Model of care**

	THEME	Description
	<b>ACCESS</b>	Connects, provides a flow of information between subjects and objects
	<i>Category</i>	
	<i>Model of care</i>	<i>A guide how best to provide equitable care across multiple domains, transitional, complex, integrated, a continuum (right care, right time, right place, right team)</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.3	<u>Patient/health practitioner relationship</u>	Historical, paternalistic, patient dependent on health professional's authority, struggle over patient's role in medical decision making
Ro1.3	<u>Communication</u>	Explain, plan, informative, person-centred, partnership, increased personal involvement
Ro1.2.3	<u>Health management</u>	Bridging the healthcare professional and the service-delivery system
Ro1.3	<u>Service provision</u>	Complex, challenging, types of services, flexible treatment and support for patients and carers, requires planning

Patient/health practitioner relationship was indexed from the identification of the continued practice of paternalistic, siloed models of healthcare delivery. The *model of care* delivered by healthcare provider(s) impacts on the partner's personal involvement in and commitment to their healthcare provision:

I don't feel I'm in a position to tell the doctor (CH16).

[H]ow many doctors really want to read our journey? (OFG2).

[I]t can't just be health professionals, it has to be us and our input is crucial (CHFG2).

I have seen the ENT specialist and physio and plastics and GP and nobody has bothered to look at it [MyHR] so therefore what's the point? (CH16).

The continued paternalistic, siloed model of engagement with health practitioner(s), affects the patient/health practitioner relationship; healthcare users become disinterested and detached from involvement in their healthcare provision.

To experience and engage with healthcare provision via MyHR, communication must be facilitated digitally. The research community narrated a readiness and willingness to engage with healthcare provision via their MyHR. However, there are those who are challenged not only by living with CCCs and by their limited computing skills, but also by service delivery: in rural communities there is limited availability of and connectivity to personal, regional and national digital communication. This needs ongoing consideration; otherwise the inability to communicate digitally in an efficient, timely manner may lead to further healthcare user disengagement:

[T]he commuter is old and so slow it'll take 30mins so I think will I do it now, and then I forget about it (LGFG2).

I don't have Internet access at home so my visits to the Internet are limited to the online centre [volunteer] or friends often (CH28).

[T]hey (NEHTA) said to me they would send me a SMS with details, well I would be stuck I would have to walk to get the message (CHFG3).

This is also evident from the researcher's journal notes and memos recorded at the time. On a number of occasions during phase two, registration and early engagement with MyHR 'wireless connectivity' was noted as 'very weak, lost or unavailable'. 'ADSL connectivity' however, 'provided no problems'.

Health management indexed positive experiences of and engagement with MyHR. As a digital object or resource, MyHR can improve the timely flow of information when it is integrated within a contemporary *model of care*. The research community narrated positive perceptions of the benefit of MyHR in their health management:

CCCs would be a lot easier to manage if the electronic health record were used (CH6).

[C]hildren that have to go to hospital. There are so many instances where this can be brilliant (CH23).

At personal, community, regional and national levels MyHR can play a role in service provision:



[A]n essential part of this electronic health record is if I went to see a Dr in QLD or fell ill (CH16).

However, not all who require transitional complex healthcare provision will require or even want to personally input information to their MyHR:

[M]y mother is 93. She still carries money and goes to the Post Office and pays her bills, she'll still want her Dr to do it (CHFG3).

although MyHR should remain central to their service provision:

[We want to] stay at home, so this [MyHR] will play a big role, all health professionals in the community will be linked and communicate (CH21).

MyHR is viewed as an essential part of service provision. There is a service provision role for MyHR at personal, community, regional, and national levels, but unless they are supported, not all healthcare users will view or personally add to their MyHR.

The data indexed to four labels: patient/health practitioner relationship, communication, health management and service provision, and charted to *model of care*. *Model of care* charted a requirement for a comprehensive digital approach to transitional complex care, which advocates the contemporary characteristics of quality healthcare provision required for a population at risk. A contemporary *model of care* can bring about change in the experience of and engagement with healthcare provision that satisfies the person requiring care. The relationship people have and their ability to communicate with their *health provision* requires a proactive, integrated, person-centred *model of care* that offers equitable **access** via *MyHR-A*, which in turn influences the availability, capacity, and overall quality of their *health provision*.

#### 4.3.5.2 MyHR-A

*MyHR-A* describes the digital ability to support the delivery of person-centred quality *health provision* and provide for a digital transitional complex *model of care* for people and communities living with CCCs. At interviews and group meetings during each phase of data collection the partners provided data that was indexed to four labels, charted to the category *MyHR-A* and mapped to the theme **access**. These are presented in Table 32, which links them to the research objectives and provides a

brief description of each label, category, and theme. A research perspective and an example of narrative follow.

**Table 32. MyHR-A**

	THEME	Description
	<b>ACCESS</b>	Connects, provides a flow of information between subjects and objects
	<i>Category</i>	
	<i>MyHR-A</i>	<i>Australia's electronic health record; has the ability to digitally support the delivery of equitable, person centric, integrated healthcare provision</i>
<b>Research objective</b>	<u>Label</u>	
Ro1.3	<u>Access to health information</u>	No longer only a health professional requirement but also an individual's requirement
Ro1.2	<u>Diverse access needs</u>	A diverse population has diverse needs—one size does not fit all
Ro1.3	<u>Opportunity</u>	The value of inclusive healthcare
Ro1.2.3	<u>Access to MyHR</u>	Connection to MyHR

Access to health information was indexed from the expression of a need to connect with, view, and interact with health information. MyHR can facilitate this:

[T]he remoteness can make it harder to access medical information. It [MyHR] makes it available ... and if the records are there you're all on the same page (CH23).

The frustration with the current access to health information was overt:

[S]o now I have to ring back and get a break down of the [results], whereas if I had it in there [MyHR] I could see them ... (LFG2).

I would have thought the Dr to see your own notes [Personal Health Note] about your current state of health is a fairly important thing (CHFG1).

Diverse access needs was indexed from experiences of and engagement with MyHR:

[It] has to have a user-friendly site. If the site is not user friendly if I have to keep pushing buttons [I'll] go off and do something else (CH12).

[I]t's [MyHR] overcomplicated ... the fact people have to ask how to use it, means it's not right (CH16).

[E]verybody has different needs ... you need time (L2).

Diverse access needs indexed the experience of and engagement with MyHR. The research community narrated that gaining access to the site was frustrating. However, at group meetings the verbalised negativity was responded to with practical positive solutions:

[S]tart with [my.gov.au] and work through, this could be rolled out by libraries (OFG3).

[O]nline centres could be used far more effectively; have trained personnel in these centres offering assistance (LFG3).

[S]omething that places could run information session groups where people come together and get through that process ... there is a role for rural primary health to play in support of that ... at the online centre or in a health centre, attached to a computer (CHFG3).

Opportunity indexed the necessary elements for engagement with MyHR and the envisaged value of a future ability to be involved in inclusive healthcare provision:

Grey nomads this is an excellent way forward, an opportunity, a portable GP (CH11).

[A] wonderful way for health, you got the person and the Dr involved, helping and giving the Dr the best chance to help you (CH28).

Access to MyHR indexed discussion focusing on security, privacy, and consent for access to MyHR. The research community did not indicate a concern about lack of or too little privacy or security. The researcher envisaged that there might have been hesitancy about privacy and security when uploading personal details online, however this did not prove to be a concern. In contrast, the community expressed concern with the overwhelming level of password protection, describing it as too much security and challenging the cumbersome, and in some cases confusing, processes that are required for regular interaction with MyHR. Access to MyHR indexed to research community frustration. However, as the researcher's journal recorded 'facilitation identified where support was required and solutions were offered':

It's fast enough to get username. I still keep losing it. I need to store it somewhere (CH1).

The security is a bit too much. Username, password then three questions and then the government one, username I'll never remember it makes no sense (CH12).

I have tried to get on and got onto the government website and couldn't find it [MyHR] and wondered am I going on to the right thing? So I stopped ... I was afraid it was the wrong place and I'd put too much in the wrong place (CH23).

The data indexed to four labels: access to health information, diverse access needs, opportunity and access to MyHR that charted to *MyHR-A*. *MyHR-A* charted an opportunity to support the delivery of quality healthcare provision. *MyHR-A* embedded in a *model of care* can provide contemporary **access** to the digital

transitional health requirements of all users and provide flexible options to interact with comprehensive quality *health provision* and health information.

#### 4.3.5.3 Health provision

*Health provision* describes the way healthcare and health services resources are combined to facilitate health interventions. Linking the categories indicates that contemporary *health provision* should be supported by and support a *model of care* that embeds *MyHR-A*.

At interviews and group meetings during each phase of data collection, the partners provided data that was indexed to three labels, charted to the category *health provision*, and mapped to the theme **access**. These are presented in Table 33, which links them to the research objectives and provides a brief description of each label, category and theme. A research perspective and an example of narrative follow.

**Table 33. Healthcare provision**

	THEME	Description
	<b>ACCESS</b>	Connects, provides a flow of information between subjects and objects
	<i>Category</i>	
	<i>Health provision</i>	<i>The way resources such as communication, staff, equipment and services are combined to allow individuals access to health interventions</i>
<b>Research objective</b>	<u>Label</u>	
RO1.3	<u>Access to healthcare providers and services</u>	Fair and equal, removing barriers regardless of geographical location
RO1.3	<u>Availability of information</u>	Physical, social elements, integrity
RO1.3	<u>Healthcare provider sharing of information</u>	Collect, store, provide access to, use and disclose: a person should have access to their personal information

Access to healthcare providers and services indexed the comments from experiences of living in rural locations. Those living in rural locations described access to healthcare providers and services as inconvenient, time consuming, and expensive. Safety was of utmost concern: the unpredictability of living with CCCs and the variability of road conditions that worsen in extreme weather all constrain access to healthcare providers and services:

[T]here isn't a specialist here in Tas for [CCCs] there's only physiotherapist I was seeing ... I haven't been for ages because it's just such a chore [length of travel when unwell and inconvenient appointment times] (CH12).

[I]t's an hours trip just to get there [to GP] so I can't just go down all the time because we can't afford another truck ... the roads and gravel round here is so unpredictable (CH22).

Availability of information indexed the availability of personal health information for those who live in rural locations, not only at a local level but also nationally, and in some instances internationally. Availability of information is required across all levels of healthcare provision:

Everything should be available on this [MyHR] for every medical practitioner. We want a national or international record of what you've been doing what's prescribed for that patient and we let the patients have access to it (CH16).

[T]he hospital should be able to go into their database put my name in double check and confirm they now have access to my record .... If they know I have a [MyHR] they then know I want the information uploaded (CHFG1).

Understanding and valuing the importance of healthcare provider sharing of information demonstrates a concern that health information is currently not being completely shared by their healthcare providers at either professional or personal levels, despite requests. This identifies a considerable health risk and a gap in healthcare provision:

The Dr needs to listen because they're missing a lot of stuff (CH23).

If my other Dr had what was it, access, then he could see my [CCCs] stuff and stuff like that. It wasn't a problem to me but it's a problem to [them]. I know it's my record but that was [them] and it was [their] point of view and [their] choice (O3).

I worry if they [HPs] aren't putting the information in [MyHR], if I go to a different hospital I want the information there, paramedics should have the information (CHFG3).

The professionals should do it and we should see what they have done (CH16).

There is however, optimism about future healthcare provider sharing of information:

[O]ur Dr is forward thinking so, fingers crossed, they may change their thinking (OFG2).

Health professionals will eventually not be able to say no (CH28).

The data indexed to three labels: access to health providers and services, availability of information, and health provider sharing of information that charted to *health provision*. *Health provision* charted the way in which healthcare is accessed and delivered as perceived by the partners. It draws attention to the uniqueness and differences in the quantity and quality of healthcare provision available to rural

populations. Quality of healthcare provision is a recurring reason for the existing disparities in experience and engagement in *health provision*. These disparities may occur because of personal commitment, information sharing, availability of information, and quality of local healthcare resources.

**Access** to contemporary quality *health provision* requires the appropriate choice of *model of care*, which embeds *MyHR-A* proactively, empowers and engages all stakeholders, and addresses some disparities of healthcare provision.

#### 4.3.6 Summary access

The theme **access** was mapped from *model of care*, *MyHR-A* and *health provision*. This section has provided analysis exemplars of **access** as essential for involvement in quality healthcare provision. **Access** is a requirement to be valued, an opportunity to obtain, use, or benefit from something or someone. Acknowledging the research community's requirement for open engagement and continuity of health information between themselves, family, community, and healthcare provision ensured that **access** links to the themes of **self-identity** and **knowledge** and the overall research objectives displayed in section 1.2.2.

**Access** is a prerequisite for quality digital healthcare provision for a vulnerable population, and to bring about change in their experience of and engagement with healthcare provision. Equitable **access** requires an innovative, proactive, digital model of healthcare.

**Access** to MyHR provides the opportunity to meet the digital transitional care requirements of all healthcare users, and gives flexible options to interact with diverse comprehensive quality healthcare provision and accurate health information. **Access** draws attention to inequalities in the quantity and quality of healthcare provision available to rural populations. **Access** to quality healthcare provision requires the appropriate choice of model of healthcare, which embeds MyHR proactively, empowers and engages all stakeholders, and recognises disparities of care.

For rural communities experiencing similar concerns in similar situations, **access** provides reassurance and opportunity; community activities and healthcare provision assist in the sharing of experiences and learning. Quality digital healthcare provision

should be an equitable, integrated, person-centred, community focused model of healthcare. MyHR, embedded in a proactive digital model of healthcare provision, has the ability to support digital **access** for all stakeholders and ultimately improve participation, capacity, and the overall quality of health outcomes.

#### 4.4 SUMMARY OF THEMES AND IDENTIFICATION OF FINDINGS

This section provides a summary of the themes and identifies 16 potential findings prior to offering nine findings.

The research community were empowered to share their **self-identity** through their participation in a facilitated process to experience and engage with MyHR. By building on their existing capability and **knowledge** and facilitating personal and group conversations, MyHR was positively identified as providing person-centred **access** that valued **self-identity** and personally and contextually relevant **knowledge** within a quality model of healthcare. The research community provided evidence to support their requirement for **access** to and engagement with their digital healthcare provision. This expanded their existing **knowledge** by offering **access** to the previously limited real-world evidence of relevant health information. The research community viewed MyHR as an opportunity to be included in the exchange of health information provided to the right person in the right place at the right time, in an effort to optimise quality healthcare provision.

The three themes **self-identity**, **knowledge** and **access** were generated from the data by reviewing narratives within and between the partners' interviews, group meetings, and researcher's reflective journal, indexing the data to labels, charting to categories and finally mapping to themes. The process was influenced by *a priori* and emerging concepts generated from the data.

As described in section 3.4.5.4, further interrogation of the data and themes exposed possible explanations for what was happening within the data and generated 16 potential findings. Further inspection revealed that some potential findings were linked across more than one theme. Scrutiny between the themes and the 16 potential findings established nine findings; these refinements are presented in Table 34. The nine findings will be interpreted in Chapter 5.

**Table 34. Themes, 16 potential findings refined to nine findings**

Theme	Sixteen potential finding	Nine findings	Nine finding headings (Chapter 5)
Self-identity	➡	Engagement with contemporary healthcare provision requires sensitivity to personal and contextual relevance	Substantive relevance
Self-identity	➡	People living with CCCs in a rural community need to be valued and included in all their transitional complex healthcare decisions	Inclusion and value
Self-identity	➡	We must ensure that a person transitioning through the course of CCCs and digital health experiences does not become defined as a 'disease' or a 'patient' or be 'stolen' by technology	Communication
Self-identity, Knowledge & Access	All of the partners have or are still using a computer, professionally or personally	Motivation and supported use of the computer and MyHR allowed the partners to learn and transition at their own pace	Learning environment
Self-identity & Knowledge	The research community gained general computing confidence and competencies		
Self-identity & Knowledge	Supported use of the computer and MyHR allowed the research community to learn and transition at their own pace		
Self-identity & Knowledge	The research built on shared experiences, the awareness and understanding of information, becoming familiar with their community, their resources, the computer and MyHR	The partners changed their perception of the community's and their personal health needs	Partnerships
Knowledge	The research changed perceptions of the research community's and personal health needs		
Knowledge	The partners learnt that they were not alone; they had their CCCs and MyHR experiences acknowledged and confirmed by the research community. They shared and learnt ways to cope with illness and using MyHR		
Knowledge	Using the computer allowed the community to seek out and store information and connect with others	Experience of and engagement with MyHR progressed to finding ways of personalising MyHR	Community knowledge
Self-identity, Knowledge & Access	Through use and discussion the community found the idea of using MyHR led to an increased knowledge of MyHR and a changed perception of computer use		
Knowledge & Access	As the community became more experienced and engaged, discussion progressed to finding ways of personalising MyHR		
Knowledge & Access	➡	People with CCCs, those who need MyHR most, need the most support	Accessibility
Knowledge & Access	As the research community gained familiarity with MyHR, they identified where modifications could be made that may be beneficial and that may fit more closely with aspects of their health needs	The confidence and competence of all users of MyHR need to be considered	Confidence and competence
Knowledge & Access	The competencies of all users need to be considered as they develop. As the community acquired competency, a range of design issues emerged. Not only experienced users should provide feedback. There needs to be a comprehensive feedback mechanism		
Access	➡	MyHR is a healthcare tool	Interoperability



## 4.5 SUMMARY

Chapter 4 has presented an in-depth systematic data analysis with respect to identifying evidence and linking that evidence to the research objectives outlined in section 1.2.2, which ultimately identified nine findings. Applying a thematic framework approach and adhering to the principles of CBPR guided a rigorous, transparent and systematic data analysis.

Data from each partner interview, group meeting, and the researcher's reflective journal were handled methodically. Representations of the research community's characteristics and their experiences of and engagement with MyHR were thoroughly explored and consistently displayed. Descriptors for each label, category, and theme were tabulated. Examples of the narrative indexed to labels, charted to categories and mapped to themes were provided. The thematic comparisons provide evidence to ensure quality research. Although the data demonstrate general agreement, by demonstrating where conflicting and contrasting views arise the researcher believes that value and credibility have been achieved. A summary is provided at the end of each theme.

Data analysis linked the research objectives to 55 indexed labels that were charted to 13 categories and mapped to three themes. Further interrogation of the data and themes generated 16 potential findings. Some potential findings were linked across more than one theme. Scrutiny of the themes and the 16 potential findings established nine findings.

The data analysis increased the understanding of a vulnerable community's experience of and engagement with MyHR, and clarified why the community believes that MyHR should be embedded in their digital complex care pathways. This serves to better inform all stakeholders including system developers, healthcare service providers, healthcare managers, government bodies, and healthcare pressure groups, but most of all, healthcare users.

Chapter 5 offers an interpretation of the nine findings.

# Chapter 5: Interpretation of findings

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Chapter 5 provides an interpretation of the nine findings identified through the iterative process of data analysis explained in Chapter 4. The chapter is organised into the following sections:

- 5.1 briefly introduces the aim of the chapter, which is to interpret the results of the nine research findings;
- 5.2 substantive relevance: discusses that engagement with contemporary healthcare provision requires sensitivity to personal and contextual relevance;
- 5.3 inclusion and value: discusses that people living with CCCs in a rural community need to be included and valued in all their transitional complex healthcare decisions;
- 5.4 communication: discusses that we must ensure that a person transitioning through the course of CCCs and digital health experiences does not become defined as a ‘disease’ or ‘patient’ or be ‘stolen’ by technology;
- 5.5 confidence and competence: discusses the need to consider the confidence and competence of all users of MyHR;
- 5.6 accessibility: identifies that people living with CCCs, those who need MyHR most, also need the most support;
- 5.7 interoperability: recognises MyHR as a healthcare tool;
- 5.8 partnerships: discusses how the partners changed their perception of their personal and community health needs;
- 5.9 learning environment: discusses how motivation and supported use of the computer and MyHR allowed the partners to learn and transition at their own pace;
- 5.10 community knowledge: discusses how experience of and engagement with MyHR, progressed to finding ways of personalising MyHR;
- 5.11 provides a summary of Chapter 5 and introduces Chapter 6.

## 5.1 INTRODUCTION

This chapter aims to interpret the nine research findings and continues to demonstrate linkages between the findings and the research objectives identified in section 1.2.2. People living with CCCs in a rural community experienced and engaged with MyHR as an opportunity to review their current healthcare provision, to view and add to the longitudinal course of their CCCs, and as fundamental to providing successful transitional digital complex care pathways. The nine findings acknowledge that people living with CCCs in a rural community have the capability and the skills necessary to identify and address the transitional requirements of their unique CCCs and to engage with MyHR.

## 5.2 SUBSTANTIVE RELEVANCE

Engagement with contemporary healthcare provision requires sensitivity to personal and contextual relevance
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People living with CCCs in a rural community require that MyHR has substantive relevance in order to gain experience of and engagement with MyHR. In context, substantive relevance was realised by the partners and the groups personally and contextually engaging with MyHR and connecting it with what they already know, living with CCCs in a rural community. Their experience of and engagement with MyHR emphasised a need for substantive relevance, which was described as a need to take responsibility, apply knowledge, develop greater knowledge, and have the opportunity to be involved in the early identification of changes in health events, prediction of illness, and timely intervention, ultimately resulting in improved quality of healthcare provision:

[B]ecause I can never remember, you go to a Dr and they say ‘how many operation have you had’ and I could never remember you panic and you think OMG. So now I know they are all there I can say it’s in MyHR (CH6).

The vulnerable community required personal and contextual connections with MyHR that engaged them emotionally and associated the concept of MyHR with their previously acquired knowledge of living with CCCs in a rural community. Collaborating as a research community achieved substantive relevance for MyHR. This ensured that their perception of MyHR was that it was interesting and worth knowing about. Without establishing such substantive relevance on both emotional and knowledge levels, the partners may have disengaged and lost motivation with the research topic.

The recognition by the vulnerable community that the opportunity to experience MyHR could be useful established substantive relevance. This was enabled by their inviting a known and trusted advocate to support them through the process of experience and engagement, and to facilitate discussion about MyHR, their own lives and what they already knew.

None of the partners in the research community had experienced or engaged with MyHR prior to the research. By suggesting that they experience a contemporary way to become involved with their healthcare provision, MyHR challenged their current way of communicating their CCCs, health and wellbeing. Genuine community and personal stories allowed the partners to become invested emotionally, and discussion emphasised substantive relevance by identifying and understanding the need to take responsibility and be involved in their quality healthcare provision.

The research community considered their experience of and engagement with MyHR to be relevant, interesting, and worth knowing. This was also achieved by early recognition and valuing to ensure personal and contextual relevance. The partners' engagement with MyHR provided value. There was a realisation that they had the potential to play a significant role in having ownership of and taking responsibility for their health outcomes and health information. Adding health data and informing their healthcare providers of their actions identified substantive relevance for their engagement with MyHR. How the content fit into their future healthcare provision was considered relevant. Substantive relevance was identified by the partners defining and communicating their personality, their CCCs, and their main problems during their CCCs transition.

As early adopters of MyHR, the research community understood that realistically they might encounter scepticism and resistance when they asked their healthcare providers to engage. Despite this, the partners welcomed the opportunity to experience and engage with MyHR, narrating that the personal information that they included in their MyHR and provided during the research would be immediately relevant as a resource for personal reflection and self-efficacy, future community research and development, and future MyHR adopters. Further, they informed their family, wider community and healthcare providers of their experience of and engagement with MyHR, suggesting that they would all benefit from engagement, thereby immediately increasing the possibility of MyHR achieving critical mass. The research community believe that, given time to build trust and a clear explanation of its substantive relevance, MyHR will be adopted nationally.

Healthcare providers need to identify and establish substantive relevance through their experience of and engagement with MyHR to contemporise and improve integrated healthcare provision. If this can be achieved, personal and community involvement in and ownership of CCCs may increase and assist in reducing the physical and psychological burden of these health needs on all healthcare provision.

Substantive relevance was recognised by the facilitation of the research community's experience of and engagement with MyHR as contextually relevant and integral to their person-centred care. By utilising *form* versus *function*, the *function* of the intervention (for people living with CCCs in a rural community to experience and engage with MyHR rather than being provided with a standardised information kit), the research community was encouraged and enabled to *form* or tailor their own ways of experiencing and engaging with their SDHR.

If substantive relevance can be facilitated through the provision of meaningful activities that emotionally engage healthcare users and healthcare providers alike and connect with what they already know, there is reason to believe that MyHR will help improve complex communications by building connections and commitment. The delivery of relevant contemporary rural healthcare provision, information about wellbeing and resources are essential to create continuous, consistent communication and learning between patient and provider.

### 5.3 INCLUSION AND VALUE

People living with CCCs in a rural community need to be included and valued in all their transitional complex healthcare decisions
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Including and valuing the contribution that people living with CCCs in rural communities make to their healthcare provision requires consideration of their literacy, language, culture, and learning styles. In context, healthcare information imparted via MyHR needs to be more inclusive than written paper-based information to reinforce healthcare-provider explanations of health problems and treatments. The experience of and engagement with MyHR needs to address and value the diversity of literacy, language, culture, and learning styles of healthcare users to:

- improve their knowledge and understanding of CCCs;
- improve their confidence and ability to be involved in decisions;

- improve their clinical outcomes;
- prompt them to implement health behaviour changes.

The distinctive personalities, lifestyles and cultural attributes of the research community required an inclusive approach to the experience of and engagement with MyHR, i.e., an approach that valued their distinctive literacy, language, culture and learning styles.

Over time, experts in healthcare provision have developed their own language or ‘jargon’. Although the use of ‘jargon’ in digital healthcare provision may simplify communication between members of expert technical groups and healthcare providers because fewer words are needed to discuss concepts and practices, the use of ‘jargon’ in health system/care provider/user relationships becomes a ‘secret’, excluding language:

The headings are wrong. There is no logic. It’s more difficult than it needs be. It’s overcomplicated. Shared Health Summary - is jargon, it doesn’t need a sub heading and the fact people have to ask how to use it, means it’s not right (CH16).

The research community’s experience and perception of their current healthcare provision is one of being excluded and undervalued. The aim of quality healthcare provision is to be inclusive and communicate beyond the experts. The use of plain language can help expand the knowledge of healthcare users who have unique experiences, education, and interests that they are more than willing and able to share. The less ‘jargon’ used in all healthcare system/provider/user relationships, the more inclusive healthcare provision becomes, ultimately reducing the physical and psychological burden of CCCs on all healthcare provision (compliance, duplicate visits, errors made because of misunderstandings).

During their engagement with MyHR, the research community developed new ways of thinking about their healthcare provision. They wanted to access supplementary healthcare provision via MyHR, explaining it as an opportunity to be included, organise, make sense of, and add value to the transitional requirements of their CCCs. Their having access to and integrating with an organised approach to their digital healthcare provision can achieve this.

However, the overall format of MyHR was deemed awkward and unsuitable. The research community/partners challenged and identified practical refinements to digital access and design. Their experience of access to MyHR identified that the security was cumbersome and onerous. Once they had gained access to MyHR, the language used was perceived as technical and clinical ‘jargon’ and the overall design of MyHR was perceived to be needlessly

complicated and confusing. Essential areas for emergency data, and information about preventative and public health were either absent or hidden.

Once engaged with MyHR, the section headings and numerous ‘call out’ tabs were viewed as a confusing on-screen intrusion, and the research community preferred the option of plain English rather than paternalistic clinical ‘jargon’. They perceived value in being able to contribute to MyHR via the Personal Health Notes and Personal Health Summary, but they considered that, rather than the system dictating access, healthcare users should be able to choose whether their healthcare provider had access to their Personal Health Notes. However, they wanted the ability to share their Personal Health Notes with their healthcare providers so that the information could provide valuable contextual understanding and assistance in future consultations.

The partners agreed, without prior discussion and agreement with their healthcare provider, that healthcare users should not have the ability to edit or exclude any health data uploaded by their healthcare provider. This was regarded as being a risk to their health, healthcare provision, collaboration and the overall future management of their CCCs.

The fact that emergency contact, allergy, and medication details were embedded within the Personal Health Notes and Personal Health Summary sections of MyHR was regarded as a lack of foresight and contrary to their understanding of one purpose of MyHR; i.e., to be a readily accessible SDHR. The partners regarded emergency contact, allergy, and medication details uploaded to MyHR as essential information in their all too common cases of emergency.

The lack of a readily identifiable facility to personally record and share preventative health information such as details about smoking, alcohol, blood pressure, weight, and public health information caused frustration. While child health and vaccination schedules were available, there was no facility to readily record and share adult vaccination status.

Literacy, health literacy and in the case of MyHR, eHealth literacy, needs to be considered. Providing access to or the sharing of any personal information requires clear, practical detail about what, how and why information is being shared. This involves the concepts of trust, relevance, engagement and taking time to explain and explore any uncertainty in the understanding of which details are being shared with whom and why. Ignoring these obligations can and will lead to misunderstandings and marginalisation, which will in turn

lead to resistance to and failure of the introduction of any SDHR. For the research community, their experience of and engagement with MyHR required:

- inclusion: engaging in collaborative relationships in an environment of mutual trust and honesty established through effective communication, and strengthening each other to feel capable and empowered;
- valuing and respecting the partners as healthcare and MyHR users who learn, who can and will process relevant information, as well as react to changes in information;
- delivering the experience of and engagement with MyHR in a personal and contextually relevant way;
- placing people living with CCCs in a rural community as central in decision-making about their healthcare provision.

If MyHR is to be more effective than paper-based information in imparting healthcare information, and in reaching people living with CCCs in rural communities to reinforce healthcare providers' explanations of health problems and treatments, interventions must be specifically targeted in personal and contextually relevant ways to achieve improved knowledge and understanding of CCCs, confidence, and ability to be involved in decisions, clinical outcomes, and health behaviours.

This can be achieved by:

- healthcare providers adopting and implementing literacy, language, culture, and learning styles and values sympathetic to the community and healthcare user;
- healthcare providers and SDHR developers, with assistance from public, medical and specialised libraries, improving clinical standards for health and care records, to support healthcare providers who wish to create a SDHR that makes it easier for healthcare providers to communicate with each other and with healthcare users.

If these inclusion and value barriers can be overcome, there is reason to believe that people living with CCCs in rural communities will engage and benefit more from MyHR than those from less vulnerable groups.



## 5.4 COMMUNICATION

While transitioning through the course of CCCs and digital health experiences, we must ensure that a person does not become defined as a 'disease' or 'patient' or be 'stolen' by technology

If the relevant information is communicated appropriately, people with CCCs living in a rural community can play a central role in communicating and understanding the causes of their illness, protecting their health and taking appropriate actions, choosing appropriate treatments for acute episodes of ill health, and in the everyday management of their CCCs. In context, ensuring that each healthcare encounter is communicated appropriately requires the experience of and engagement in equal, trust-centred relationships between healthcare users and providers, each accepting the other's responsibility and ability to:

- process information and react to changes in information;
- establish nonlinear interdependencies with multiple care providers (including nonverbal communication);
- create order in a system without a clear hierarchical direction;
- allow the environment to influence each other's decisions and development.

Each partner in the research community required ongoing support from more than four healthcare providers. Most partners described themselves as their disease: I'm diabetic, asthmatic (CH1), rather than as a person living with a disease, e.g., 'I have diabetes and asthma', or by the number and frequency of healthcare appointments that they have to attend:

I got the [CCCs] nurse to make an appointment in [Town] next Thursday... straight after one another all at the [hospital]. I haven't had my strength and balance test from a physio for a while so I'm doing the whole lot (O1).

This is because healthcare provision has communicated paternalistically with them as patients or referred to them in silos of disease. People living with CCCs make lifestyle compromises because of their inability or unavailability to access health, social, recreational, physical, and cognitive stimulation and the potential of burdening others. Those who cannot, or require additional support to, perform conventional tasks and social obligations lose the capacity and motivation needed to maintain their established lifestyle. Without the development of an equally valued lifestyle, there is a possibility of a decline in physical and psychological health and a change in identity: they accept being defined and communicated with as a 'patient'.

Their experience of MyHR involved and motivated the people living with CCCs to resume or assume personal responsibility, engage, recognise, and question their role in the management of their multiple CCCs, and disclose their concerns. Engaging with MyHR provided the basis for a longitudinal SDHR, a personal shared health summary of their multiple CCCs. Engaging with MyHR exposed their capability and vulnerability. The sharing of information identified resilience and the potential to build resilience, and the capacity to communicate and to reduce their overall burden of physical and psychological health issues.

Using digital technology allows a person who is compromised by their reduced ability to verbally communicate or to remain socially independent beyond the home environment to remain involved and to build alternative social communities and family communication networks. Those who struggle with digital technology, partly because of their CCCs but in most cases because of their fear of inability or failure, require support to become engaged and empowered. If it is communicated in a supportive and relevant way, digital technology can emphasise doing rather than being and provide an opportunity to be personally responsible, engaged and integrated with their healthcare provision.

However, those who use and value digital technology as their only source of family and community communication and socialisation may risk social isolation. Their personality may become defined by how they engage with their digital community or family, a ‘like’ or a ‘nice’; they lose contact with and the skills required to engage in their real world. Their ideas form and are confirmed by what they read, rather than being endorsed by what they say, feel, see, smell, or touch. They become defined by how they engage with digital technology:

I’m not talking to people as much, I feel I’m talking into myself ... I just click like and type nice as long as they know that I’m there taking part (O1).

People living with CCCs in a rural community play an important role in understanding the causes of their illness, protecting their health and taking appropriate action, choosing appropriate treatments for acute episodes of ill health, and managing their chronic illness. These roles must be recognised and supported to ensure that a person does not become defined as a ‘disease’ or ‘patient’ or as ‘stolen’ by technology. Healthcare providers can ensure that, wherever possible, people living with CCCs, who are the most likely healthcare users, are involved in communications and making informed decisions about their healthcare. The partners believed that what people living with CCCs want most of all is relevant, quality, healthcare provision and that information is available at specific transition stages. They want:

- communication whereby they can express their experience and emotions;
- to engage with the process to increase their understanding and knowledge of everything involved in the ongoing transition;
- to find the path that allows them to regain some order in their lives;
- to learn the skills to allow them to work independently through situations as they arise in the future.

Mainstream clinical information and facts about CCCs are not always appropriate to everyday living and the management of CCCs. Of more interest to those living with CCCs are treatment options, factors for success (prognosis), and how to obtain support to manage their CCCs. If people living with CCCs are to play an active role in decisions about their future care, they need to be encouraged and empowered by well-trained healthcare providers. This requires enabling healthcare user communication, engagement, and empowerment activities including:

- local coaching and advocacy to increase people's confidence in taking a proactive communication role in consultations;
- continued provision of healthcare provider development courses that repeatedly integrate communication skills;
- engagement with or continued use of MyHR, as a prompt with questions to ask in the form of access to events and shared health summaries from previous consultations and the creation of topic lists for later discussion.

For a person living with CCCs, engaging with MyHR as an empowerment technique can increase their knowledge and recall and their feeling of involvement in their care, reduce misunderstanding and marginalisation, and improve the healthcare user/provider relationship. For the healthcare provider, engaging with MyHR as an empowerment technique may increase clinical continuity and improve their knowledge of how living with CCCs affects and effects the concerns of the person living with CCCs.

If these communication barriers are overcome, it would be possible to make a significant difference in the contextual knowledge about CCCs and the way people with CCCs communicate with healthcare providers. This would not increase costs, but may actually

reduce them by improving healthcare user and provider understanding, and by reducing the number and length of healthcare provision sessions required and prescriptions issued. Improved medication compliance also increases the chance that treatment will be effective.

## 5.5 CONFIDENCE AND COMPETENCE

The confidence and competence of all users of MyHR need to be considered

People with CCCs living in a rural community require confidence and competence to engage with MyHR. In context, confidence was achieved and competence acquired as the partners experienced and engaged with MyHR. As they became experienced with using MyHR, their fear diminished and their confidence grew. As their confidence grew, they became competent at engaging with MyHR:

I haven't written the day I stopped smoking in there [MyHR] yet. It's in my book, I'll put it on because I've got to catch up with a lot of things, it only takes a little while to punch the numbers. I should of thought about adding the smoking thing I'll get that in (O2)

Experience of MyHR was perceived as a positive contemporary innovation in the delivery of and access to quality healthcare provision across Australia. When this diverse community identified the opportunity to experience and engage with MyHR in a comprehensive, collaborative, coordinated, community partnership, they quickly became confident and competent in engaging with MyHR.

Supported through their experiences of and engagement with MyHR, the research community became knowledgeable and resourceful, providing an irreplaceable source of personal and contextual real-world information. A key component to achieving confidence and acquiring competence in using MyHR was the sensitive facilitation process, which:

- recognised the developing interactive partnerships between the partners, the groups and the facilitator;
- gained rapport with a diverse community culture, recognised their needs, and tailored their experience of and engagement with MyHR accordingly;
- recognised a diverse community with complementary knowledge and skills;
- conducted iterative assessment, feedback, and problem solving;

- recognised that people can ultimately succeed (and let them know you believe in them);
- recognised the value of encouragement to try (and supported them to reduce the fear factor);
- recognised the value of encouragement in the effort (stimulated confidence);
- gave people the resources to develop competence (training and coaching);
- helped them see their potential and skills (encouraged them to try again).

The research community appreciated the opportunity to be involved in solving their problem and being asked for real-user feedback regarding MyHR. Once they were confident and competent in their engagement with MyHR, they requested that all their healthcare providers adopt the system to upload their health information, and that they personally have access to all their health information. All health providers declined their requests. However, the research community reported that they found having access to engage with MyHR personally useful and empowering, despite the absence of healthcare provider involvement and information. Those partners who voiced dissatisfaction with access to MyHR qualified their comments, implying that the unwillingness of their healthcare provider to engage with MyHR resulted from the healthcare providers' misunderstanding and marginalisation of the capability and importance of the healthcare users' contribution to their healthcare provision.

The partners were committed to implementing a change in the way they communicated and integrated with their healthcare provision. They were committed to experiencing and engaging with MyHR, regardless of their cognitive ability and their physical, psychological and social presentations. However, when they approached their healthcare providers, they met resistance. Trusted healthcare providers did not want to change their processes, preferring to continue to deliver paternalistic, siloed models of healthcare to a vulnerable community living with multiple CCCs. While this model of healthcare provision persists, vulnerable healthcare users will continue to be marginalised by limited healthcare provider choice and have to accept suboptimal care.

The healthcare providers' continued delivery of paternalistic, siloed healthcare and their refusal to experience and engage with MyHR could be interpreted as resistance to change. If these concerns are not adequately addressed, they have the potential to cause increasing safety

and quality issues in healthcare provision. Non-sharing of health-relevant information can be misleading, lead to misdiagnosis, duplication of effort and medication errors, and in some cases, put other healthcare providers, the community, and the person seeking healthcare provision at a serious health risk. Healthcare providers are and will remain responsible for the health and social care information they collect or divulge in any format: MyHR does not change that responsibility.

The denial of a request for knowledge via the contemporary healthcare provision MyHR leads to questions about the currency of the communication competency of the healthcare provider. In addition, by redirecting a clinical conversation to another topic, comfortable for the healthcare provider, that provider sends a message to the healthcare user that they are being misunderstood and marginalised. This is not the provision of person-centred, integrated healthcare, and confirms the concern about paternalistic, siloed models of healthcare provision.

Within the current healthcare provision environment, there is a bureaucratic approach to the introduction and early implementation of MyHR. This has failed to engage the real users, healthcare users and healthcare providers. The research community believe that, like themselves, healthcare providers require relevant, contextual facts about what, how, and why information is being shared, and the experience and evidence to be able to trust MyHR. Prior to healthcare provider engagement, they should be offered time for explanation and exploration of uncertainties and understanding. As with the partners, without meeting the obligations of practical contextual explanation, building trust and allowing time, healthcare providers will remain sceptical and resistant. This will result in failure of the introduction of any SDHR.

Healthcare provider engagement with MyHR can be achieved by addressing their scepticism, which is currently creating a gap in the delivery of quality healthcare provision for people living with CCCs in a rural community. Healthcare providers should address their resistance to relinquishing control and allowing healthcare users access to their health information.

An everyday core competency of any healthcare provider is timely efficient communication and effective information management. In a quality healthcare environment, up-to-date knowledge and use of SDHRs should be obligatory for appropriate transitional complex healthcare provision. For the healthcare provider, knowledge of and engagement with MyHR

should be regarded and valued as a best-practice adjunct in the delivery of all quality healthcare provision.

If the confidence and competence barriers of healthcare users and healthcare providers alike can be overcome, it is possible to make a significant difference in the way people with CCCs living in a rural community and their healthcare providers engage with MyHR in the provision of person-centred, integrated healthcare.

## 5.6 ACCESSIBILITY

### People living with CCCs, those who need MyHR most, need the most support

The research community was receptive to experiencing and engaging with MyHR. However, accessibility for some was challenging. Not all people living with CCCs are physically or cognitively capable of performing all the tasks required to fully engage with and contribute to MyHR. In context, there is a real possibility that people living with CCCs have one or more physical and/or neurological impairments. To experience and engage comprehensively with MyHR requires the early recognition, engagement and support of carers, family, community, and the collaboration of all their healthcare providers:

It's up to [carer] to do all the typing for me because well to use the keyboard that often the letters are disappearing, I don't know where they are but also I'm very slow and touch the wrong key sometimes (CH19).

Physical or neurological impairments such as poor vision, physical tremors, and mild cognitive impairment should not exclude anyone from participating in MyHR. The partners recognised their decreasing ability to remain active and acknowledged that their long-term independence might be challenged. Despite disclosing multiple CCCs, less than half the community reported regular carer support. Some underestimated or completely failed to recognise the silent informal everyday carer support provided by their family.

Digital technology and SDHRs are becoming fundamental to the requirements of quality transitional healthcare provision for people living with CCCs. However, for those without the agreed engagement and support of their carers, family, and community (whether or not they are described as 'carers') and collaboration with all their healthcare providers, independent engagement with MyHR will remain an obstacle.

A person living with CCCs should be encouraged to accept and acknowledge the role of the informal carer as an advocate and identify them as such in MyHR. Informal carers should be

encouraged, with permission, to play an active advocacy role in MyHR for the person living with CCCs as part of their ongoing care provision. The information in MyHR may then be used to open up discussions about identified vulnerabilities and to plan appropriate preventative and long-term care, e.g., by ensuring that a clear statement of their advanced care wishes<sup>9</sup> has been discussed and documented with both their informal carer and their professional healthcare providers:

I need to know what's going on if he's not capable and be able look at the past and be able to record details about him to share with health professionals (CH23).

For those people living with CCCs who require additional support with their contemporary healthcare provision, this requires:

- the early identification, recognition of and support for the role of the informal carer, as an advocate in all contemporary healthcare provision;
- the provision of additional support for the healthcare user and informal carer during their early experience of engagement with MyHR;
- identification and recognition by healthcare provider(s) of the invaluable role of the informal carer and MyHR in the transitional healthcare provision required of a person living with CCCs.

Ensuring that all health information is communicated and uploaded to MyHR in a manner that is sympathetic to the user's physical and cognitive capabilities can improve knowledge and understanding of CCCs for the healthcare user, the informal carer, and the healthcare provider. If these accessibility barriers can be overcome, it is possible to make a significant difference in the way personal and contextual knowledge and understanding of CCCs are delivered for the healthcare user, informal carer, and healthcare provider.

## 5.7 INTEROPERABILITY

MyHR is a healthcare tool
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<sup>9</sup> Advance care planning is a process for making and writing down future healthcare wishes in advance. What is written in an Advance Care Plan only comes into effect if and when the person becomes unwell and is unable to make or communicate those wishes for themselves. Medical treatment, including surgery, should only be given with the person's fully informed consent. They have the right to refuse any treatment. If the person becomes seriously ill, information in their Advance Care Plan will guide their family and doctor when making medical treatment decisions on their behalf.



MyHR was experienced and engaged with as a contemporary tool for healthcare documentation. However, for this engagement to be comprehensive MyHR must have interoperability with point-of-care testing (POCT) devices, diagnostic testing, and imaging requests and reports. In context, people living with CCCs in a rural community require the right healthcare provision tool to go with their needs for healthcare provision, so that they engage with it in the best way to deliver the most value.

The research community experienced, engaged with, and shared ways of using MyHR. This engagement extended beyond the research community because they shared their new knowledge and the value of MyHR throughout their families and wider communities. The partners identified an issue that was important and relevant to themselves; the research focus was on their experience of and their engagement with MyHR in order to observe, record, and report opportunities and weaknesses, and ultimately to make engagement with MyHR personally and contextually relevant. Their tailored experience of and engagement with MyHR created an opportunity and allowed time to build trust, question, and challenge their community. Their experience of and engagement with MyHR was perceived as valuable: ‘so obvious you wonder why it’s not there already’ (O4) and ‘one person, one health, one record’ (CH23). One SDHR that succinctly contains their longitudinal health history allows the complete sharing of health information, which can increase timely diagnosis and treatment and reduce duplication of effort and medication that have traditionally had the potential to put the healthcare user at a serious health risk.

However, for MyHR to be engaged with as a comprehensive healthcare tool, the research community also required that it have interoperability with POCT devices, diagnostic testing and imaging requests, and reports. MyHR interoperability should provide rural healthcare users with viable access to comprehensive shared digital healthcare provision.

If it [MyHR] was linked to the [POCT program] then my GP could see that. [System developer] have access and the [clinic]. Needs to be available to all [healthcare providers]. Would make it a lot easier. A PDF would be better than nothing. This [POCT] program can calculate different info depending upon what you want (CH1).

Currently, healthcare users using the facilities of digital POCT devices communicate their results directly between themselves, the healthcare provider and the POCT system developer. Because of the lack of interoperability between MyHR and the POCT device, healthcare users and providers are currently expected to engage with a minimum of two digital resources; MyHR for documentation and their POCT device(s) for upload of clinical tests. This is a

burdensome duplication of effort, is inefficient and importantly, is a risk for the quality and safety of information from healthcare users and providers.

Further, it is understandable that this current lack of interoperability between POCT devices, investigation results and imaging, and MyHR may be regarded or used as a reason why healthcare providers remain sceptical and reluctant to engage with MyHR. For healthcare providers to find utility in MyHR requires evidence that it is an improvement on their current model of healthcare provision; currently there is no such evidence. Interoperability of MyHR is vital if this contemporary method of healthcare provision is going to reduce inefficiencies and ensure or improve quality and safety for all.

If these interoperability barriers can be overcome, MyHR should make a significant difference in the way personal and contextual knowledge and understanding of CCCs are communicated between the healthcare user and healthcare provider, thus reducing the risk of duplication of effort and miscommunications.

## 5.8 PARTNERSHIPS

### The partners changed their perception of their personal and the communities' health needs

The research community learned that they were not alone; their lived experiences with CCCs and MyHR were acknowledged and confirmed by the trust and partnerships established in their groups. In context, establishing trust around shared experiences of and ways of living with CCCs and engaging with digital information and MyHR in a rural community encouraged and empowered partnerships:

[I]t helps in the long run; things are getting done, people are finding out about more diseases and things like that, it's got to be an improvement, to find out these things. It's an opportunity especially a rural community like this. It helps, it gets people together, they discuss things and it makes it a lot better I'm sure it does. I think the diversity of the group is wonderful (CH6)

Working together allowed familiarity, value and respect to establish partnerships through shared experiences of CCCs and their awareness and understanding of information, their community resources, ICT and MyHR. Knowledge and expertise developed through familiarity within the context of the rural community. Identifying the commonalities or differences in complex problems such as the transitional requirements of a person's CCCs, development or further development of their ICT skills and their experience of and

engagement with MyHR provided an equitable platform upon which the partners comfortably shared and developed their knowledge and skills.

The focus of the research was problem solving. By committing to and becoming involved as a rural community partnership, the research community identified and embraced the opportunity to problem solve, share capabilities, and further develop:

- an understanding of the multiple CCCs;
- new competencies and confidence in the use of ICT for seeking and storing information;
- communicating and discussing health information gaps and the concept of MyHR embedded in their transitional healthcare provision.

Engagement positioned the partners centrally within the future healthcare provision requirements of their CCCs. Encouraging and empowering the partnerships with experience, knowledge, and skills regarding rural community resources, CCCs management, the role of and their engagement with MyHR achieved this.

The partnerships provided an often-overlooked rural community with the opportunity to make a lasting contribution by consistently focusing on personally and contextually relevant problems, via discussions of how their rural healthcare provision and their engagement in MyHR can benefit provision of future digital transitional care for CCCs, while considering the impact for other communities. The partnerships demonstrated an awareness and capability of considering the big picture without losing the essence of who they are:

There was a discussion today about the national usage... thinking about the context of a bigger national system rather than just our local [community] (CHFG3)

The research community not only gained practical knowledge but also provided real-world knowledge: their understanding of living with CCCs and their experience of and engagement with MyHR. MyHR was regarded as a worthwhile form of communication, collaboration, and documentation, allowing healthcare user involvement in their digital transitional CCCs care provision and in future research.

To achieve this requires:

- building environments where community partnerships, value, and respect flourish for personal and contextual CCCs transitions;

- developing knowledge through the use of trust in capability and familiarity within their rural community;
- acknowledging commonalities and diversity, of complex problems such as the transitional requirements of each person's CCCs, development or further development of information and computing skills, and the experience of and engagement with MyHR.

These actions provided a base upon which the partnerships could comfortably share and develop knowledge and expertise. Ensuring a community experience requires trusted partnerships and joint decision making that address:

- personally and contextually relevant concerns that can contribute to an improved outcome for the community;
- early community engagement and empowerment in all processes that are identified and built upon;
- collaboration, exploration and recognition that develop and acknowledge new and different expertise;
- ensuring a lasting contribution to the community and research.

If the barriers to developing trusted relationships and identifying capabilities can be overcome, it is possible to build partnerships. These can make a significant difference in the way contextual knowledge and understanding of CCCs, ICT skills, and the experience of and engagement with SDHRs (for the healthcare user, healthcare provider, and researcher) enable learning environments and co-produce information.

## 5.9 LEARNING ENVIRONMENT

Motivation and supported use of the computer and MyHR allowed the partners to learn and transition at their own pace

Partnerships developed and supported the learning environments required to experience and engage with MyHR. In context, this was achieved by facilitating learning environments where personally and contextually relevant explanations of ICT and MyHR were established:

We're starting and learning together the same as learning computer together you share so much instead of individual and sometimes that role, how do I get back to it? Working with buddies you always learn by how somebody uses something (CH16).

The partners required an awareness of ICT use. This was not considered a research recruitment prerequisite and did not appear in the inclusion or exclusion criteria discussed in section 3.4.1 and listed in Table 9. However, all the partners had access to a personal or laptop computer, and all had or were currently using ICT in some capacity. During data collection, it was noted that the MyHR did not provide an application for easy access to the SDHR. Some believed ICT to be invaluable while others were less convinced. Prior to their experience of and engagement with MyHR, the attitude of the partners toward ICT use and utility revealed the reasons why they elected to use or not to use a computer.

The current use of ICT was mostly described as valuable in the context of professional, personal, and educational access and usefulness. Those partners who described having less experience of or being sceptical about the use of ICT developed a willingness to experience ICT and MyHR once they were involved, supported, and motivated by their group and their family, and shared their achievements with the research community, family, and healthcare providers. The partnerships supported and developed a learning environment where the partners became involved in experiencing and engaging with MyHR at their own pace.

During the early experiences of MyHR, those partners who disclosed computer inexperience also voiced uncertainty; however, with support and motivation they gained confidence and competence and engaged with MyHR.

[P]ut it all on there now and then I've got an easy reference for the Dr or whoever you know (O2).

A supportive and motivated learning environment was achieved by the development of partnerships. The learning environment provided time to question and explore the reasons for uncertainty, scepticism, and current non-use of ICT. Facilitating the research community, at their pace, through their multiple transitional complex decisions required:

- development of a structure of realistic community and personal goals and actions; the use of personal and community storytelling was an effective way of exploring concerns and explanation of, for example, ICT skills and how MyHR could work;
- providing live access to experience and engage with MyHR and allowing sufficient time for the real users to understand the options offered by MyHR;
- ensuring attainable opportunities were made available and acceptable to all; letting their own creative capabilities surface, allowing them to test the relevance of MyHR in

their own time and space, and log their experiences themselves or with the support of their family/carer;

- that the researcher allowed sufficient time for storytelling and MyHR testing improved the post-intervention data analysis; the use of post-intervention interviews provided an in-depth understanding of the partners' experiences, while using groups provided comparison and validation.

A supportive learning environment provided even those who in the first instance presented as inexperienced or sceptical with the capability and confidence in their ICT skills to ultimately engage with MyHR. However, this finding also draws attention to the situation of vulnerable healthcare users who have, or choose to have, limited ICT availability. While healthcare providers remain peripheral to the delivery of person-centred care and sceptical about engaging with or even experiencing MyHR, healthcare users may be accepting inferior health outcomes.

The continued isolation and marginalisation of the vulnerable healthcare users, people living with CCCs in a rural location who have limited access to and interaction with healthcare provision, will expose problems as they transition through their complex care needs. These could include, for example, the risk of lost records, duplication of clinical effort, and ineffective communication leading to missed early recognition of declining health and early access to healthcare intervention. Acceptance by vulnerable healthcare users or their healthcare provider of infrequent, paternalistic, siloed models of healthcare provision cannot deliver quality digital healthcare provision appropriate for a person or rural community living with CCCs.

If supportive learning environments can be established in vulnerable communities, it should be possible to make a significant difference in the way contextual knowledge and understanding of CCCs, ICT skills, and the experience of and engagement with MyHR by the healthcare user, healthcare provider, and researcher co-produce information and community knowledge.

## 5.10 COMMUNITY KNOWLEDGE

Experience of and engagement with MyHR progressed to finding ways of personalising MyHR
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Community knowledge can inform wider establishments of the real-world experience of and engagement with MyHR. In context, community knowledge was perceived as a collaboration and exchange on how to optimise the experience of and engagement with MyHR.

Community knowledge includes contextual information, facts, and data that are available for sharing. Community knowledge includes ‘how’ and ‘know-how’, the ability, capacity, and understanding to turn knowledge into action. The creation of community knowledge was identified by the way the research community developed partnerships and learning environments to experience and engage with MyHR by:

- demonstrating comprehension of CCCs and the capability to be involved in shared healthcare decision making;
- documenting their health in MyHR and demonstrating confidence and capability in engagement with MyHR.

Community knowledge gathered the abilities to narrate, write and organise their lived experiences of CCCs and engagement with MyHR. By demonstrating an understanding of CCCs and confidence and capability in engagement with MyHR, the partners assumed a central role in achieving their personal health goals: to better engage, prepare to share their health information, and communicate with their healthcare providers. Working together as a research community allowed them to learn and demonstrate how individuals, groups, and communities can use, create, and share community knowledge to spark real social change.

You need as much info as possible; I think getting a story is getting as much information as possible. By asking a question you’re getting the info on those lines only. It’s a matter of getting communities involved quite honestly to. I think the community knowledge is very underestimated by people doing research and I know various things have been done around [southern midlands] the council have bought in outside consultants without consulting the local people at all and one or two moves have been patently not good and a waste of money (O4)

Community knowledge increased the partners’ ownership and provided evidence of their involvement with their health, CCCs, ICT, and experience of and engagement with MyHR. Discussions provided evidence of:

- awareness of local and digital information resources;
- expertise in ICT and engagement with MyHR;

- increased confidence, and for some, a changed perception of the utility of digital technology.

Community knowledge transformed those partners who, in the first instance, viewed ICT or MyHR as an additional unnecessary resource, another language to learn, a threat, or an uncomfortable change. Collaboration of knowledge provided motivation and supported their opportunity to gain and provide community knowledge about health, CCCs, and MyHR. In doing so, community knowledge increased their personal capability and identified community value in shared digital healthcare provision.

The collaborative discussions about community data supported communication and exploration, expanding and explaining ICT skills and knowledge. A change was seen not only in the research community but also in their use of and challenges to MyHR. The research built on research community experience by leading toward engagement, with the research community becoming very comfortable with collaboration and explanation. MyHR provided an equitable concept, new to all, which allowed demonstration and questioning of accumulated knowledge. By discussing and challenging the concept of MyHR, invaluable information was identified that was directly useful to the partners, community, and future research and development of SDHRs:

This is an opportunity for ourselves working as a community to bring our comments and skills together and provide structured research feedback and hopefully bring about change (OFG3).

Building partnerships and learning environments garnered community knowledge. Raising and sharing awareness of local and digital information and available resources increased community knowledge; local group meetings combined and developed each partner's knowledge and expertise. Ownership progressively enhanced community and personal understanding of health, CCCs, ICT, and MyHR requirements. Experience of MyHR led to increased awareness of their ICT competencies and confidence and changed their perception of the usefulness of digital technology.

If trusted supportive learning environments can be established in vulnerable communities, it is possible to gather valuable community knowledge and ultimately, to make a significant difference in the way knowledge and understanding of CCCs, ICT skills, and the experience of and engagement with SDHRs for the healthcare user, healthcare provider, and researcher are collected and communicated.



## 5.11 KEY RESEARCH FINDINGS

When the research community were facilitated through their experience of and engagement with MyHR, they clearly narrated an understanding of their complex health and healthcare requirements and identified and established the benefits of MyHR. Learning and adapting to new and contemporary ways of living with and communicating the requirements of their CCCs is a life-long transitional process.

People living with CCCs in a rural community have established and continually adapt to personal and contextual routines, where they know what and when changes may be possible. Healthcare provision alone cannot and should not presume to know exactly what is required and when, or how it should be accomplished. MyHR can and should be regarded as a contemporary opportunity for people living with CCCs to:

- describe and present their understanding of their lived experience with CCCs;
- be involved in their healthcare provision and have their opinions respected, trusted, valued, and acted upon.

The consequences of these experiences and perceptions were highlighted during the interpretation of the nine findings. By systematically interpreting these findings and considering them in relation to the research questions, identified in section 1.2.3, three key research findings have emerged:

**Tailored Facilitation** - facilitation tailored to recognise the diversity of healthcare user's needs can instil and support the competence and confidence required for acceptance of a SDHR.

**Tailored facilitation** is described as the building of elementary partnerships and the sensitive tailoring of the intervention to the diverse needs of each partner and group. Linkages between the findings and **tailored facilitation** are seen by recognising that facilitation of the research community and individuals required substantive relevance, which enabled motivation and trust and developed partnerships and iterative learning environments. In these findings, **tailored facilitation** is perceived as a critical element in exploration of the experience of and engagement with MyHR that ultimately provided irreplaceable community knowledge.

**Resilience** - vulnerable healthcare users demonstrate and build **resilience**, which can inform contemporary healthcare provision and the implementation of an SHDR. **Resilience** is

described as an adaptive life-long process of continual learning, a way of coping and adapting to new ways of living with CCCs. Linkages between the findings and **resilience** are demonstrated by the research community's and partners' requirement for substantive relevance, their ability to identify the need for inclusion, value and communication, their development of confidence and demonstration of competence, their recognition of the need for accessibility and interoperability, their building of partnerships into learning environments, and finally, their willingness to share skills, expertise, and knowledge for the benefit of their family, community, and wider community.

**Reflection** - reflection on the benefits and challenges of applying a CBPR approach to digital health research demonstrates benefits that would not have emerged through a researcher-focused paradigm, and challenges that required strong researcher–community partnerships developed over time, with trust and flexibility on all sides.

The research describes **reflection** as an exploration of the benefits and challenges of the CBPR approach to enable vulnerable healthcare users to engage in research while also becoming adopters of digital health tools. **Reflection** moves away from **tailored facilitation** and **resilience**, which focus on the substantive vulnerable healthcare user experience of and engagement with MyHR. **Reflection** focuses on whether the CBPR methodological approach has achieved improved outcomes in relation to the adoption, use, and value of SDHRs in vulnerable communities. **Reflection** is a finding that reinvigorates CBPR as a methodological approach.

These key research findings generate knowledge and offer insight into approaches to real-world use and applications that can support implementation of SDHRs. In chapter 6, these will be described, with an explanation of how they have answered the research questions, and critically discussed with the appropriate evidence.

## 5.12 SUMMARY

Chapter 5 has presented an interpretation of the nine findings: substantive relevance, inclusion and value, communication, confidence and competence, accessibility, interoperability, partnership, learning environment, and community knowledge.

Each section has presented the findings related to the overarching objectives of the research, described in sections 1.2.2. In summary the research community demonstrate that:

- People living with CCCs in a rural community require substantive relevance to benefit from the experience of and engagement with MyHR. Sensitive facilitation achieved this by relating MyHR to the contexts of everyday, personal factors and living with CCCs in a rural community.
- Recognising, involving and valuing the contribution that vulnerable people and communities can make to their quality healthcare provision requires consideration of: literacy, language, culture, and learning styles. Rather than being regarded as a deficiency of the person, rectified by education, they should be recognised as a deficiency of the system, rectified through community and organisational changes.
- When MyHR is considered as a shared digital healthcare repository to communicate and collaborate, it can provide a valuable resource that can achieve the timely management of CCCs without accentuating transitional ‘disease’ or ‘patient’ processes. Communication and collaboration via MyHR can reduce unnecessary defining healthcare visits, improve access to healthcare provision and reduce cost.
- People with CCCs living in a rural community require confidence and competence to engage with MyHR. This can be achieved by developing interactive partnerships, recognising the diversity of a community with complementary knowledge and expertise, sensitive facilitation, iterative assessment, feedback, and problem solving, belief and encouragement, and the provision of resources to develop competence.
- People living with CCCs, i.e., those who need MyHR most, need the most support. Not all people living with CCCs are physically or cognitively capable of performing all the tasks required to fully engage with MyHR. Engagement requires recognition of and support for the role of the informal carer as an advocate in all contemporary healthcare provision.
- For healthcare users to engage with MyHR as a comprehensive healthcare tool and for it to be considered inclusive requires interoperability with POCT devices, diagnostic testing and imaging requests, and reports.
- Developing partnerships acknowledged and confirmed the lived experiences of CCCs and MyHR. Partnerships can be achieved by recognising unique expertise, knowledge, and experiences, which raise awareness of available resources and identify different approaches to attaining and documenting health information in MyHR.

- Person-centred learning environments were enabled through the partnerships. These learning environments recognised community resources, computer availability, internet access and the potential of engagement with MyHR. However, for these vulnerable communities, limited access to resources and MyHR may expose future problems as they transition through their complex healthcare requirements.
- Community knowledge is required to inform wider establishments of the real-world experience of and engagement with MyHR. Community knowledge can be garnered by taking time to support, involve, enquire, learn, and contextualise a role for MyHR. Empowering people living with CCCs in a rural community to engage and understand the requirements of MyHR provided an opportunity for efficient quality digital healthcare provision. The new knowledge created about practical issues that effect and reflect the community, can influence wider establishments to better understand quality healthcare innovation and bring about change.

Chapter 6 will describe the three key research findings, **tailored facilitation**, **resilience**, and **reflection**, explain how they have answered the research questions, and critically discuss them alongside the appropriate evidence.

# Chapter 6: Discussion of key research findings

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Chapter 6 describes the three key research findings, **tailored facilitation**, **resilience**, and **reflection** that emerged from considering the nine findings in relation to the research questions identified in section 1.2.3. This chapter explains how **tailored facilitation**, **resilience**, and **reflection** have answered the research questions and critically discusses them alongside the appropriate evidence. To achieve this, Chapter 6 is organised into the following sections:

- 6.1 briefly reintroduces the research questions and introduces the key research findings;
- 6.2 describes the key research finding **tailored facilitation**, explains how it has answered the research questions and provides a critical discussion related to the appropriate existing evidence presented in Chapter 2;
- 6.3 describes the key research finding **resilience**, explains how it has answered the research questions and provides a critical discussion related to the appropriate existing evidence presented in Chapter 2;
- 6.4 describes the key research finding **reflection**, explains how it has answered the research questions and provides a critical discussion related to the appropriate existing evidence presented in Chapter 3;
- 6.5 provides a summary of Chapter 6 and introduces Chapter 7.

## 6.1 INTRODUCTION

This chapter has two aims, to explain the significance of the key research findings in the context of answering the research questions and to explore the significance of the key research findings. This section briefly reintroduces the research aim and questions and introduces the key research findings.

**Ra.** To emphasise practical outcomes identified by exploring the experience of people living with complex CCCs in a rural community engagement with Australia's shared digital health record, MyHR.

The research questions considered:

**Rq1.** What is the experience of MyHR for people living with CCCs in a rural community?

**Rq2.** Why do people living with CCCs in a rural community engage with MyHR?

When considering the findings in relation to the research questions, three key findings emerged:

- **Tailored Facilitation** - facilitation tailored to recognise the diversity of healthcare users' needs can instil and support the competence and confidence required for acceptance of a SDHR;
- **Resilience** - vulnerable healthcare users demonstrate and build resilience, which can inform contemporary healthcare provision and shared digital health record implementation;
- **Reflection** - reflection on the benefits and challenges of applying a CBPR approach to digital health research demonstrates that it produced benefits that would not have emerged through a researcher-focused paradigm, and challenges that required strong researcher–community partnerships that were developed through time, trust, and flexibility on all sides.

## 6.2 TAILORED FACILITATION

This section describes **tailored facilitation**, explains how it has contributed to answering Rq1. and Rq2., and critically discusses **tailored facilitation** in relation to the appropriate existing evidence presented in Chapter 2.

Tailored Facilitation - facilitation tailored to recognise the diversity of healthcare users' needs can instil and support the competence and confidence required for acceptance of a SDHR

**Tailored Facilitation** assisted the research community to enter into useful discussions that enhanced their experience of and engagement with MyHR. **Tailored**

**facilitation** also assisted in the development of partners' enthusiasm and confidence to share and seek views on how MyHR should operate:

[T]his is great, everybody likes to be involved and feel they have an opportunity to give. We're starting and learning together the same as learning computer together you share so much instead of individual and sometimes that role, how do I get back to it, working with buddies...you always learn by how somebody uses something (CH13).

**Tailored facilitation** is described as elementary partnership building and the sensitive tailoring of the intervention to the diverse needs of each partner and group. Recognising and facilitating substantive relevance, an iterative learning environment, and enabling motivation and trust were critical elements in exploring the partners' experience of and engagement with MyHR, ultimately providing irreplaceable community knowledge.

#### 6.2.1 Rq1. Tailored Facilitation and experience of MyHR

Examination of how Rq1. had been answered revealed that the research demonstrated that **tailored facilitation** improved the partners' experience of MyHR. Prior to their introduction to the research, the partners had been unsure of the purpose of MyHR, and none had registered for or experienced the concept. They identified a learning opportunity to experience MyHR, thereby immediately increasing their opportunity to communicate, demonstrate capability, and access their health information. Once the research community was established they, without reservation and irrespective of their physical and cognitive ability, communicated the potential advantages of MyHR for their future involvement and engagement in their CCCs, and as an opportunity to review their healthcare provision, to view and contribute to the longitudinal course of their CCCs, and as fundamental to providing successful transitional digital complex care pathways.

Facilitating the experience with MyHR of a diverse rural community of people living with CCCs required sensitivity, understanding, and patience. **Tailored facilitation** achieved substantive relevance by valuing and supporting physical and cognitive impairment, literacy, language, culture, and learning styles. By providing a familiar environment to allow groups and interviews to listen to stories in an uninterrupted manner, hear their own words, and explore new concepts, the partners' experience of MyHR became a confident and competent engagement with MyHR.

I didn't feel educated enough to do it. That was the reason why I didn't like the computer (CH21).

During their experience of MyHR, the thinking of some partners appeared distorted by low self-esteem. The facilitator's gentle questioning and encouragement enabled them to explore their feelings, thoughts, and emotions. To correct such thinking it is important to discuss what is perceived as 'educated' or 'normal'. When talking and thinking this through, we discovered that 'normal' is only a perception. **Tailored facilitation** sensitively dispelled irrational beliefs and built personal ability, partnerships, and learning environments.

If there was a computer day ... I should have a go, my grandchildren was going to teach me.  
If there was an opportunity ... a buddy system .... My younger sister could teach me (CH21)

### 6.2.2 Rq2. Tailored Facilitation and engagement with MyHR

Examination of how Rq2. had been answered revealed that **tailored facilitation** assisted the research community's engagement with MyHR, and ensured that their engagement with MyHR remained both iterative with their experience of MyHR and substantially relevant. **Tailored facilitation** ensured the engagement of the research community, and then engaged the partners. This approach recognised that the research community functioned as a complex adaptive system (section 2.7.1.1) and also that engagement with MyHR required person-centred contributions (section 2.7.1.2).

All 19 partners engaged with MyHR and remained engaged with the research throughout. This provides evidence that **tailored facilitation** ensured that MyHR remained relevant to the research community, who had identified the opportunity to engage with contemporary healthcare provision and invited the researcher to support them. The facilitator's flexibility about group meeting and interview preferences was key in maintaining interaction and motivation. The research community learned to take responsibility both as individuals and in groups for their engagement with MyHR.

The use of local venues facilitated maximum attendance and minimum disruption for the partners, who all lived within 10 kilometres of their chosen group venue. The general nonthreatening introduction to the groups and the topics followed by a short interactive presentation and live experience of MyHR, refreshments, and further



discussion ensured that each partner in each group felt comfortable speaking freely, and encouraged ownership.

Tailored facilitation ensured that the face-to-face and telephone interviews were conducted at a time and location where partners were most likely to access and interact with MyHR. This allowed them to feel comfortable, speak freely, encouraged ownership, and provided the researcher/facilitator with an ideal opportunity to assess the partners' contextual experience of and engagement with MyHR.

Living with CCCs in a rural community emphasises multiple life issues, including the realisation that lives have changed and that the intrusion of CCCs concerns the collective lives of their family and community. For instance, the limitations of access to quality healthcare provision and financial constraints can restrict access to physical, cognitive and social stimulation. However, the research community have learned to accommodate the many challenges and changes their CCCs have brought, claiming a preference for living in a rural community.

**Tailored facilitation** not only accommodated but also learned from the in-depth knowledge and expertise of people living with CCCs in a rural community, and their ability to establish partnerships and develop trusted learning environments that generated community knowledge. This ultimately made a contribution to the way that knowledge and understanding of the lived experience of CCCs, ICT skills, and the experience of and engagement with MyHR are communicated for the vulnerable healthcare user, the healthcare provider, and the researcher.

### 6.2.3 Discussion - Tailored Facilitation

The introduction of any change typically arouses a fear or distrust of the transition more than of the idea (Martin & Sturmberg 2009). However, this vulnerable community achieved change by identifying their research topic—a need to be valued and provided with access to relevant contemporary rural healthcare provision—and inviting support from a trusted facilitator. The community acknowledged the opportunity to engage in **tailored facilitation**, thereby immediately creating substantive relevance for inclusion and value, communication, and a learning environment. **Tailored facilitation** ensured substantive relevance by connecting MyHR to everyday, personal and contextual living with CCCs in a rural community.

There have been many reports (Creer, Renne & Christian 1976; Lemmens et al. 2008; Lorig & Holman 2003; Wagner et al. 2001) discussing frameworks or models to improve self-management of CCCs, the inclusion of digital health technologies, and the barriers for vulnerable populations (Gordon & Hornbrook 2016; Graetz et al. 2016; Kontos et al. 2014; Showell & Turner 2013). However, there is little contextual evidence supporting modified models of quality healthcare provision for people living with CCCs who require transitional healthcare provision (Greenhalgh et al. 2015; Lenert et al. 2014), or suggesting that the use of **tailored facilitation** with vulnerable healthcare users during the introduction of digital health technologies increases their engagement with SDHRs.

This research extends previous evidence by offering insight into approaches that increase the acceptance of SDHRs. **Tailored facilitation** supports the vulnerable healthcare user's experience of and engagement with MyHR by entering into relevant personal and group discussions. It motivates and instils personal and community confidence and competence to experience, seek out and exchange views on how and why MyHR may be beneficial. **Tailored facilitation** draws attention to four issues for discussion:

- evolving trust-centred relationship between the groups, the individual, and the facilitator;
- valuing a diverse community with complementary skills;
- iterative cycles of experience, engagement, feedback, and problem solving;
- the need for a sensitive facilitator who can gain rapport with each group and individual, assess their needs, and tailor their experience of and engagement with MyHR accordingly.

The eHealth Initiative (2012) maintains that vulnerable communities typically lack the insight and expertise to understand and fulfil instructions regarding their transitional CCCs requirements. On the contrary, this research demonstrated that the community identified an innovative opportunity and committed to a trust-centred relationship. **Tailored facilitation** ensured that each persons' experience of and engagement with MyHR at both emotional and knowledge levels, supported their

need and want to develop and, importantly, to share skills and knowledge while accessing and contributing to their contemporary healthcare provision.

**Tailored facilitation** allowed the evolution of trust-centred relationships. A community working in partnerships and with the facilitator assisted in defining their own contemporary health needs and developing their experience of and engagement with MyHR. The facilitator's role was to gain rapport sensitively and to assess the personal and group needs through iterative cycles of experience, engagement, feedback and problem solving. Understanding that the information they provided was to be shared with wider establishments, a diverse community willingly contributed their expertise, shared in decision-making processes and demonstrated ownership.

Bandura (1997) recognised that involving and integrating people living with CCCs, increased their understanding about their capabilities and identified options for redefining existing healthcare provision models. However, current evidence-based practice continues to translate conceptual models of person-centred healthcare provision (Wagner et al. 2001) and complex adaptive systems (Leykum et al. 2007; McDaniel Jr., Lanham & Anderson 2009) within a narrow, doctor-defined 'patient's agenda' (Greenhalgh et al. 2015, p. 1), failing to evolve trust-centred relationships or tailor information as substantively relevant for the healthcare user.

By including and valuing the diversity of a community with complementary skills, this research respected people living with CCCs as agents within a complex adaptive system who have the ability to learn and understand and who want interconnections, are prepared to co-evolve, and demonstrate their capability for self-organisation. As a result of tailoring the intervention to include and value the diversity of the individuals and by sensitively recognising their complementary skills, a community collaborated and perceived MyHR as a resource that ultimately enabled their involvement in and greater understanding of early identification of changes in health events, prediction of illness, and the requirement for timely intervention of quality healthcare provision.

The evidence suggests that accessing quality healthcare provision, particularly when living with CCCs a distance from the caring services or away from home and community, is a barrier that can be overcome by having a complete SDHR (AIHW 2016; Bodenheimer et al. 2002; eHealth Initiative 2012; Pefoyo et al. 2015; Roland

& Paddison 2013). However, there is little evidence to demonstrate how this is being assessed, implemented, or supported. This research extends previous knowledge by suggesting that the provision of **tailored facilitation** encouraged a community to experience and engage with MyHR. In doing so, they demonstrated their requirements, understanding, responsibility, and capability through iterative cycles of personal and group experience, engagement, feedback, and problem solving, ultimately providing evidence about issues confronting the community's quality healthcare provision.

The evidence also draws attention to the numerous different healthcare providers who require access to the digital health record of a person living with CCCs at any one time (Almutairi 2011; Heard et al. 2000). Again, there is little evidence in Australia to demonstrate that this is happening, or how it is being implemented or maintained. This research recommends that **tailored facilitation** and the use of *form* versus *function* can demonstrate that the experience of and engagement with MyHR is substantively relevant to individuals and groups. For example, to garner the research community's experience of and engagement with MyHR, the *function* of the intervention was perceived to be an exploration of the experience of and engagement with MyHR by people living with CCCs in a rural community. Rather than using the standardised and distributed leaflets and information, the individuals worked collaboratively to *form* or tailor their own ways of experiencing and engaging with MyHR. Employing the idea of *form* versus *function* is a concept that is transferable to other communities.

MyHR should support many roles in quality healthcare provision (Almutairi 2011; Heard et al. 2000). This includes providing equitable access for all healthcare users, whose health information it contains. **Tailored facilitation** i.e., taking the time to listen, support, involve, enquire, learn, and contextualise a role for MyHR, identified engagement with MyHR as beneficial for vulnerable populations living with CCCs in a rural location, who have limited interactions with quality healthcare provision.

A vulnerable community demonstrated the ability to engage with MyHR and expressed their need for access to their complete health information, for communication and collaboration and an exchange of information between the family, community, healthcare providers, and routine and specialist healthcare

provision. However, despite requesting an ‘upload’ of their Shared Health Summary to MyHR, shared access to information prepared by healthcare providers and shared via MyHR was not possible.

This inability of a vulnerable healthcare user to access their Shared Health Summary following a request for ‘upload’ confirms the evidence that healthcare providers are reluctant to change the process, preferring to continue to impose a narrow doctor-defined ‘patient’s agenda’ on people living with multiple CCCs, who have limited provider choice and have to continue to accept care focused on a brief medical encounter (Charmaz 1983; Eysenbach & Jadad 2001, p. 6; Greenhalgh et al. 2015; Martin & Sturmberg 2009).

While healthcare providers continue to consider healthcare users as ‘threatening intruders trespassing into a forbidden zone’ (Eysenbach & Jadad 2001, p. 6) vulnerable healthcare users will remain marginalised and continue to receive suboptimal healthcare from paternalistic healthcare provision. Healthcare provider knowledge of and engagement with MyHR should be regarded and valued as a best-practice adjunct in the delivery of all contemporary healthcare provision.

The transitional complex needs of a person living with CCCs require a person-centred approach from the perspective of a complex adaptive system. This includes open and timely collaboration and communication with the providers of different expertise, guaranteeing that all healthcare options are explored and offered (Battersby et al. 2003; Bodenheimer et al. 2002; Jordan et al. 2008). Limiting access to MyHR for these vulnerable communities exposes future problems as they transition through their complex care needs. These problems could include the missed early recognition of declining health, early access to a healthcare intervention, and duplication of healthcare provision (Charmaz 1983; Homko et al. 2008; Pefoyo et al. 2015; Roland & Paddison 2013; Wan, Vo & Barnes 2012). Further, continued acceptance by a person living with CCCs or their healthcare provider of infrequent paternalistic, siloed models of healthcare provision cannot deliver the WHO (2016b) requirements for quality, digital integrated healthcare provision much needed in vulnerable communities.

SDHRs consistently fail to appropriately address essential requirements of healthcare users (Arsand & Demiris 2008; Briones 2015; Czaja & Lee 2002; Homko et al.

2008; Rowsell et al. 2015; Spriggs 2013; van't Riet et al. 2001). **Tailored facilitation** empowered individuals and groups to demonstrate their MyHR needs to ensure that all personal capabilities are taken into consideration and that contingencies are identified if obstacles are experienced.

**Tailored facilitation** extends current knowledge by suggesting that complete engagement with MyHR, for most vulnerable healthcare users, requires modifications to its design. People living with CCCs in rural communities are, given appropriate opportunity, likely to be frequent users of MyHR. They require consideration; they are probably mature adults for whom the requirements of all basic tasks of living need to be taken into account. Currently, MyHR does not fully realise its potential because the system designers have failed to value real users' requirements of MyHR: to support person-centred, context-aware care from a complex adaptive systems perspective. These challenges include, but are not limited to, literacy, health literacy and eHealth literacy levels, CCCs-related changes, and functional abilities such as sensory-perceptual processes, motor abilities, response speed, and cognitive processes. Rather than being regarded as a deficiency of the person or community, these needs should be viewed as a deficiency of the system, and rectified through systemic changes to community healthcare provision.

MyHR can and should be regarded as an opportunity for research and design of quality healthcare provision that is accessible and engaging for all users. If MyHR is to enable person-centred care from a complex adaptive system perspective, system developers and healthcare providers need to acknowledge and rectify its deficiencies. All contemporary health information needs to transition from system/digital or clinical 'jargon' to provide comprehensive guidance that makes information clear and accessible to everyone, irrespective of their physical/cognitive ability or system knowledge.

During this research, partnerships developed into learning environments that increased personal knowledge of community and digital information resources, which in turn improved personal and community health and wellbeing knowledge in the context of MyHR. The principles of CBPR (Hills & Mullett, 2000) guided the practical, equitable, inclusive, and empowering experiences.

Embedding individuals as a research community in the generation and analysis of data enabled comparison, collaboration, and communication, which stimulated expertise in exploring, expanding, and explaining (Bristowe, Selman & Murtagh 2015; Kitzinger 1995). Using the CBPR methodology to explore the experience of and engagement with MyHR was relevant: it enabled real people in a real community to tell their stories, an effective way to collect explanations, and allowed them time and creativity to experience and democratically challenge all options for MyHR. The strong collaboration within the research community extended and created new knowledge about practical issues that reflect and affect the community, and may influence wider establishments to understand better, accept innovation, and bring about change.

The key finding **tailored facilitation** contributes and extends current evidence by generating community knowledge. The research illustrates how **tailored facilitation** was supported by the evolving trusted-centred relationships based upon sensitivity to and understanding of the diverse backgrounds of individuals and communities, and allowed evidence-based practice, goal setting, problem solving, flexibility, and space for learning, all of which created an iterative process of experience and engagement with MyHR. However, if **tailored facilitation** is to be replicated successfully it must be ensured that the facilitator receives adequate support, appropriate training, and has the skills to ensure a strong collaborative relationship and replicate the successes identified from this research.

**Tailored facilitation** can lead to substantial and sustainable improvements in the experience of and engagement with MyHR for vulnerable populations. It holds promise as a method to advance population experience and engagement with MyHR.

### 6.3 RESILIENCE

This section describes **resilience**, explains how it has contributed to answering Rq1. and Rq2. and critically discusses **resilience** in relation to the appropriate existing evidence presented in Chapter 2.

Resilience - vulnerable healthcare users demonstrate and build resilience, which can inform contemporary healthcare provision and shared digital health record implementation.

**Resilience** involves the ability to adapt to life events and approach sources of stress as positively as possible. **Resilience** is demonstrated in the way people cope with challenges, take opportunities, and their willingness to learn. **Resilience** can be built upon by drawing on personal strengths and abilities and by connections and support from others. The sense of support derived from belonging to a community builds a sense of optimism and motivation:

[P]eople are finding out about more diseases and things like that ... It's an opportunity especially a rural community like this. It helps, it get people together, they discuss things and it makes it a lot better I'm sure it does ... the diversity of the group is wonderful (CH6).

The research describes **resilience** as an adaptive life-long process, a process of continual learning, a way of coping and adapting to new ways of living with CCCs. **Resilience** is people living with CCCs taking the initiative to manage their symptoms and have control over how illness impacts their lives. The way people manage and their capacity for managing is individual and changes throughout the transitions of CCCs and life:

I know my body and how they [CCCs] affect me. It may not be what's written in the books but I need to communicate that .... It's me, my body I know what's really going on. I think a lot of people are going to the Drs and following what they say without question. What happens if that doesn't work for me or makes me bad? I need a two way street (CH23).

### 6.3.1 Rq1. Resilience and experience of MyHR

Examination of how Rq1. was answered showed that the research revealed that vulnerable healthcare users demonstrate **resilience** when entering into constructive discussions about their experience of MyHR. Vulnerable healthcare users demonstrated a need to build **resilience** by identifying the research topic, which reflected a concern of their community: in what capacity could a SDHR be beneficial for a person living with CCCs in a rural community, and what obstacles might they encounter. This concern demonstrates a need to accept and adapt to changing patterns of being and doing into new ways of living and being, demonstrating and building **resilience** during experience of MyHR by:

- recognising the need to be adaptive, develop a stronger sense of self-identity and build capacity to overcome adversity;



- having the opportunity to explain boundaries and work within them together with healthcare providers, so that if something happens, there is an ability to bounce back;
- developing the confidence and competence to know ... ‘we are right, that we really do feel ill, that it is not imagination or exaggeration, it is real and we have understanding of ourselves’ (OFG3).

**Resilience** is demonstrated and built upon through the lived experience of CCCs. When disruptions occur and continue to occur, the impact becomes minimised because the people have developed the expertise and **resilience** to work through the difficult times and bounce back. The **resilience** displayed by the partners and groups during their experience of MyHR informs community knowledge, which can ultimately inform contemporary healthcare provision and SDHR implementation.

### 6.3.2 Rq2. Resilience and engagement with MyHR

Examination of how Rq2. has been answered showed that the research revealed that vulnerable healthcare users convey **resilience** by their belief that they should be encouraged and have the opportunity to engage, to describe and present their understanding of their CCCs, be involved and have their opinions respected, valued, and acted upon.

The engagement of vulnerable healthcare users with MyHR demonstrates and builds upon **resilience** as an evolving learning process. MyHR can be engaged with as a resource to access health information, advise and educate others about their needs. Entering personal health details into MyHR demonstrates and builds **resilience** by providing the opportunity to think about how and what to communicate, to whom, and when.

Through engagement with MyHR, vulnerable healthcare users shared and better understood their particular experiences of CCCs and MyHR. They built **resilience** by becoming more knowledgeable and resourceful while providing an irreplaceable source of practical real-world community knowledge that is useful to the wider community and research:

Two people may have the same diagnosis but how it affects them and where they go from there can be totally different. Of course and that’s what I try to get through to a lot of people

including doctors. I know my body and how they [CCCs] affect me. It may not be what's written in the books but I need to communicate that. If that [MyHR] allows me to communicate that in some form (CH23).

People living with CCCs have established and adapted to a routine where they know what and when changes may be possible. Quality healthcare provision alone should no longer presume to know exactly what is required or when or how it should be accomplished. MyHR should be considered as a fundamental adjunct to contemporary healthcare provision that provides opportunities for vulnerable healthcare users to demonstrate and build **resilience** by:

- exploring and defining their issues and recounting their expertise and understanding of their lived experience with CCCs;
- avoiding being judged by being involved in their healthcare provision, giving their sense of their concerns about living with CCCs and exploring those issues with healthcare providers;
- developing collaborative goals and having their opinions respected, trusted, valued, and acted upon.

Shared information at every level is a practical enabler of personal and community **resilience**. Healthcare provision and community members need to work interactively and transparently to ensure that the correct information is communicated in a timely and effective manner. Full engagement with MyHR can provide a practical enabler to demonstrate and build **resilience**.

### 6.3.3 Discussion - Resilience

There is much evidence that discusses using and building resilience in tandem with individuals constructing their care in response to their CCCs (Cal et al. 2015; Gheshlagh et al. 2016; Martin & Sturmberg 2009). However, there is little evidence suggesting exploration of the demonstration or building of **resilience** in vulnerable healthcare users or their communities during their adoption or use of SDHRs.

This research extends the current evidence by suggesting that people living with CCCs in a rural community not only demonstrate but also build **resilience** when they enter into collaborative partnerships and supportive learning environments during their experience of and engagement with MyHR. Vulnerable healthcare users

identified their need for relevant contemporary rural healthcare provision and information and resources to promote wellbeing, ultimately to create continuous, consistent patient–provider communication and learning. Relating MyHR to everyday, personal, and contextual living with CCCs in a rural community established MyHR as a contemporary longitudinal resource to demonstrate and build upon their **resilience** in the context of quality healthcare provision.

**Resilience** of vulnerable healthcare users can inform contemporary healthcare provision and the implementation of MyHR. This research highlights that the **resilience** demonstrated and built upon by people living with CCCs in a rural community extends and generates new knowledge. This offers real-world insight and informs contemporary healthcare provision and SDHR implementation.

**Resilience** draws attention to three points for discussion:

- vulnerable healthcare users demonstrate and build **resilience** when entering into constructive discussions about their experience of and engagement with MyHR;
- people living with CCCs in rural communities are resilient; they want to take the initiative and be involved in managing the symptoms of their CCCs and, where possible, to have some control about how their illness impact their lives;
- the way that people living with CCCs manage and their capacity for managing is individual and fluctuates throughout their illness and their life. This requires them to engage with MyHR as an enabler of person-centred care from a complex adaptive system perspective.

The research demonstrates that people living with CCCs in a rural community are **resilient**. They want to take the initiative, be involved in managing the symptoms of their illness, and wherever and whenever possible to have some control about how CCCs impact their lives. Their **resilience** was demonstrated by their identifying their need to address the issues of equity, integration, accessibility, quality, and efficiency that confront their community, and requesting to experience and engage in MyHR as supplementary to their current healthcare provision. The research community viewed MyHR as an enabler of person-centred care from a complex adaptive system

perspective: a resource where they can demonstrate and build **resilience**, thereby enabling their greater understanding of and involvement in the identification of early changes in health events, prediction of illness, and the timely intervention of quality healthcare provision.

Although the delivery of quality healthcare provision for vulnerable individuals and communities has long been a topic for discussion in both the areas of vulnerable populations and digital health technology (eHealth Initiative 2012; Greenhalgh et al. 2009; Project Integrate 2016; Showell & Turner 2013; Whetton 2005), this vulnerable community has established real-world evidence of how **resilience** in vulnerable healthcare users and communities is demonstrated and built upon during their experience of and engagement with MyHR, an area which has not previously been explored.

The way vulnerable individuals manage and their capacity for managing is variable and fluctuates throughout their illness and their life. When MyHR is viewed as an enabler of person-centred care from a complex adaptive system perspective, **resilience** is demonstrated. People living with CCCs in a rural community consider themselves independent, and most do not define a need for regular carer support or advocacy; they independently engage with MyHR. However, those who identify a need for support for their physical, cognitive, and psychological wellbeing, openly identify a need to build **resilience** by engaging with MyHR supported by their carers and ultimately, working in collaboration with their healthcare providers. Otherwise, for them the use of MyHR will be impractical and its utility lost. The research also draws attention to the fact that those who perceive themselves as independent and do not define a need for regular carer support advocacy may be missing out on healthcare, social care, and the facilities of MyHR.

Today, it is not only older populations of people living with CCCs competing with the everyday challenges of the physical/cognitive, psychological and social impact of symptoms, disabilities, multiple medications and long-term interactions, who require a variety of healthcare provision (ABS 2016b; DHHS 2013; Martin & Sturmberg 2009; Wagner & Groves 2002). The greater the multiple of CCCs, the greater the complexity of attentions required by multiple healthcare providers, medications prescribed, and healthcare costs, leading to greater risks and greater need for precise

and efficient communication (Kamerow 2012; Martin & Sturmberg 2009; Murray, E et al. 2005; Salisbury et al. 2011; Sevick et al. 2007). All these challenges intensify the risk of an individual becoming defined personally or by family, community, or healthcare provision as a ‘disease’ or a ‘patient’, thus increasing the mental and emotional anxiety of coping with CCCs.

The evidence tends to depict a long-term condition as periodic ‘illness exacerbations’ that prompt the person living with CCCs to seek care. However, the experience of CCCs may not be as an illness, but as a fact of life and something that must be accommodated (Greenhalgh et al. 2015; Martin et al. 2011).

If MyHR is viewed as an enabler of person-centred care from a complex adaptive system perspective to allow engagement, communication, and collaboration, it can provide a resource to facilitate the timely management of CCCs without accentuating a transitional ‘disease’ or ‘patient’ process. This can be achieved by availability, enabling a demonstration of and building **resilience** in both the person living with CCCs and their informal carer, reducing unnecessary defining healthcare visits, improving access to healthcare provision and reducing cost. MyHR can facilitate **resilience** by developing understanding, collaboration, and communication of CCC requirements with all stakeholders.

As discussed in section 2.7, CCCs comprise different stages: simple, complicated, complex, and chaotic. The stages require different interventions to address the changing complex dynamic characteristics of transitional care needs of the person living with CCCs (Martin et al. 2011; Martin & Sturmberg 2009). The interaction between a person living with CCCs and their healthcare provision requires a long-term commitment to their multiple complex care requirements that ensures appropriate interventions in response to unpredictable patterns of CCCs at unpredictable times.

**Resilience** can be demonstrated and built upon by the way MyHR is engaged with, and how it is rationally viewed as a longitudinal healthcare provision resource, and by understanding engagement with MyHR as an opportunity for access, interaction, and organisation to build on personal and healthcare provider knowledge in an equitable, cohesive, sustainable manner.

Involving healthcare users in person-centred approaches to digital health research is challenging and continues to be devalued by many digital health system developers (Arsand & Demiris 2008). Most digital health research continues to focus mainly on healthcare providers in large institutions, who are easier to engage through their administrative hierarchy, rather than on vulnerable healthcare users, who face many burdens in their daily lives and are perceived as reluctant to adopt a new system (Gordon & Hornbrook 2016; Graetz et al. 2016; Kontos et al. 2014; Showell & Turner 2013).

This key finding provides evidence of how personal and community **resilience** can offer fundamental insight into real-world use and applications that support implementation of MyHR. First, relating MyHR to the lived experience of CCCs in a rural community established MyHR as a contemporary longitudinal resource. This empowered the vulnerable healthcare users to demonstrate and build upon their **resilience** in the context of quality healthcare provision. Secondly, viewing MyHR as an enabler of person-centred care from a complex adaptive system perspective recognised a resource where individuals can demonstrate and build **resilience** in their approach to and their capacity for managing their CCCs. This was achieved through their interconnection as agents willing to learn, co-evolve, and self-organise, thereby enabling greater understanding and involvement in the identification of early changes in health events, prediction of illness, and timely intervention of quality healthcare provision. Finally, MyHR can enable the demonstration of and build on **resilience** by providing access to multiple layers of healthcare provision, thereby making sense of and optimising their individual lived experiences of CCCs and building on the core values of the community vision of quality healthcare provision and empowerment of individuals.

Combining **resilience** demonstrated and built upon by vulnerable healthcare users, with engagement with MyHR as an enabler of person-centred care from a complex adaptive system perspective, can facilitate the emergence of health in individuals and communities through adaptability, self-organisation, and empowerment.

## 6.4 REFLECTION

This section describes a **reflection** on the benefits and challenges of applying CBPR principles to digital health research. It explains how **reflection** has contributed to

answering Rq1. and Rq2. and critically discusses **reflection** in relation to the appropriate existing evidence presented in Chapter 3.

**Reflection** on the benefits and challenges of applying a CBPR approach to digital health research demonstrates benefits that would not have emerged through a researcher-focused paradigm and challenges that required strong researcher–community partnerships developed through time, trust and flexibility on all sides.

**Reflection** on the benefits of applying a CBPR approach to digital health research illustrates how digital health research can be effectively translated into real-world practice. It also details the challenges associated with the approach, especially when it involves vulnerable communities experiencing and engaging with SDHRs.

**Reflection** is a key finding that strengthens CBPR as a methodological approach. The research describes **reflection** as an evaluation of the benefits and challenges of using a CBPR approach to engage vulnerable healthcare users in research while they are also becoming adopters of digital health tools. **Reflection** focuses on whether using a CBPR approach has achieved improved outcomes in relation to the adoption, use and value of SDHRs in vulnerable communities.

**Reflection** on the benefits of applying a CBPR approach to digital health research demonstrates benefits that would not have emerged through a researcher-focused paradigm. The benefits are displayed in Table 35 and accompanied by an example to provide a guide for future adopters.

**Table 35. Benefits of applying a CBPR approach to digital health research**

Benefit	Example
Relevant research	The research questions reflected a concern of the community. Group meetings and individual interviews assisted in identifying the relevance and importance of addressing trust and capacity when delivering a SDHR as an intervention Assessment of the research community characteristics revealed needs beyond experience of and engagement with MyHR, which have direct implications for healthcare providers and digital models of healthcare provision. The time and effort spent exploring SDHR requirements for the research community provided real-world evidence for digital health system developers and healthcare providers alike of the enduring capacity and requirements of vulnerable healthcare users and the changes required in the system
Wider research opportunities	The research community used their expertise, knowledge and motivation to promote SDHRs among their family, community and healthcare providers. The research community volunteered to be involved in future digital health/SDHR community research.
Effective recruitment and retention of diverse populations	The research successfully recruited and retained people living with CCCs in a rural community by: <ul style="list-style-type: none"> <li>• engaging a community based organisation that was aware of the community dynamics and individual circumstances to assist with the recruitment;</li> <li>• purposeful sampling that specifically targeted a diverse cohort of people living with CCCs;</li> <li>• involving a demographic that is underrepresented in SDHR research;</li> <li>• providing an introduction to the CBPR approach and intervention (SDHRs) to ensure</li> </ul>

	that the community were fully aware of the commitment required prior to engaging as a research community.
Improved internal validity	Iterative member checking assisted with the refining of the transcripts to themes. The iterative thematic framework approach to data analysis further provided an open flexible systematic process, perceived to be acceptable and valuable.
The translation of experience into engagement	The initial phase of the research focused on the research community characteristics and needs of the research community, quickly moving to incorporate the experience, value and requirements of a SDHR for vulnerable communities and individuals. The community and university were kept informed of the findings to ensure the work by the research community was recognised prior to publication.
Development of vulnerable communities	Some research partners continue to maintain their SDHR and continue to encourage their family, community and healthcare providers to do likewise. By regularly maintaining their SDHR the research partners are now more aware of and proactive to any adverse changes in their CCCs. They also perceive themselves as better informed during clinical consultations. Informal carer support has transitioned. Having access to a person living with CCCs SDHR is perceived as useful in performing the role of both care and advocate.

**Reflection** on applying a CBPR approach to digital health research demonstrates challenges. These required strong researcher–community partnerships that developed through time, trust and flexibility on all sides. The potential challenges are displayed in Table 36 together with the lessons learned to provide a guide for future adopters.

**Table 36. Challenges of applying a CBPR approach to digital health research**

Potential challenges	Lessons learned
Time and effort required to build relationships and trust between all involved	Developing partnerships requires appreciating various requirements: <ul style="list-style-type: none"> <li>• to use a common language and avoid jargon, clinical or digital;</li> <li>• to ensure that all meeting arrangements receive equal input from the research partners and researcher;</li> <li>• to ensure that all roles and responsibilities are clearly explained and understood by everybody participating.</li> </ul>
Community/academic mismatch structures, relationships, timings, communication styles and culture	Provide clear information sheets, consent forms and adherence to principles to avoid misunderstanding. Make all research information available in paper and digital format and repeat verbally at each encounter.
Community/academic research intervention implementation. Different vision as to how the research should be implemented	Identify and understand the basis of the research topic before implementing the research: ensure that the research design is clearly described, discussed and written down. Ensure that flexibility is built into the design to allow for emergent needs.
Identification and recruitment of appropriate community and research community	Engage and value community knowledge. This local knowledge can help recruit the research community. Throughout all phases of the research provide opportunities for flexible, iterative training and involvement opportunities. Respect that not all partners will be able or want to attend all meetings.
Share control of research by academic research and community	Share the research responsibilities between the research community, ensure time at each meeting to review the responsibilities in the collaborative process.
Succession planning for sustainability	Consider partnership and technology needs throughout the research process. Identify long-term access to technology (SDHRs) and training and expectations after the research ends.
Impact of shifting contextual factors on research	Routinely discuss immediate project changes. Understand contextual changes occur in the research community; be flexible and prepared to make project changes. Understand contextual changes in health information technology (SDHRs). Be flexible and prepared to introduce changes as they emerge.
Identification of resources and capacity (including technology)	Rather than committing the community and research to additional expense, identify and make use of available community/individual



infrastructure) required to enable community to participate as research partners	resources and infrastructure. As a research community work together to identify and build technology skills be prepared to identify and provide alternative access to technology devices and access to digital health resources (SDHR)
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**Reflection** has linked and identified the benefits and challenges of using a CBPR approach to gather the experience of and engagement with SDHRs. These will be examined in section 6.4.1 to address how Rq1 and Rq2 have been answered.

#### 6.4.1 Rq1. Reflection and experience of MyHR

Examination of how Rq1. has been answered showed that the key finding **reflection** revealed that CBPR as a methodological approach can achieve an improved outcome in relation to the experience of MyHR in vulnerable communities.

The use of a CBPR approach ensured that the community was offered an inclusive opportunity to investigate and integrate a topic relevant and of interest to them (rather than the researcher) into their experience of MyHR. The relevance of the research topic also ensured that the experience of MyHR was meaningful to the lived experience of CCCs for each partner and the research community, rather than from the researcher's perspective.

The establishment of a good working relationship with Rural Primary Health Services, Tasmania (a community based organisation) to harness their insight about community dynamics and individual circumstances, and the use of purposeful sampling, assisted in obtaining the research community's full commitment and active involvement in the research design. An introduction to the research method, design, and intervention (MyHR) ensured that the community were fully aware of the shared commitment prior to engaging as a research community. These actions ensured that the research community's experience of MyHR was acceptable and context-aware. The research community's full involvement in the research design also improved its internal validity.

Ensuring that the experience of MyHR was meaningful and context-aware required strong researcher–research partner partnerships. Building partnerships required time, effort, and trust on all sides. These skills are not regularly taught in academic settings.

Building trust required clear communication (written, digital, and verbal), the regular provision of information (including adherence to the principles of CBPR) and

building flexibility into the research design (meeting dates, venues, and the use of technological resources). These all proved important to the experience of MyHR. Thorough consideration and a flexible approach towards personal needs, community resources, and infrastructure allowed each research partner and the research community to respond to their emergent health needs and support their technology training needs and availability. Iterative training and assistance with technological and literacy skills was required to experience MyHR. Building capacity for research participation was considered crucial to the collaboration success.

#### **6.4.2 Rq2. Reflection and engagement of MyHR**

Examination of how Rq2. has been answered indicated that the key finding **reflection** revealed that CBPR as a methodological approach can achieve an improved outcome in relation to the engagement with MyHR in vulnerable communities.

Applying a CBPR approach provides benefits related to the development of vulnerable people. Engagement with MyHR empowered the research community to forge new partnerships, learn new digital-health skills and grow as leaders within their own communities. Because of the community interest in and relevance of the topic, the research community engagement with MyHR had a wider research impact. The CBPR approach led to a translation of digital health research into action. The research community's engagement with MyHR directly integrated into digital healthcare expertise and knowledge to be shared with the wider community, rather than only through standard academic research channels.

The expertise and knowledge gathered through full participation in the research and engagement with MyHR led to the research partners promoting MyHR among their families, community and healthcare providers, thus increasing the opportunity for healthcare user MyHR registration and digital health awareness.

However, the development of the research community's digital health expertise, knowledge, and engagement exposed gaps in current healthcare provision and digital health system development. Healthcare provision and digital health system developers seriously marginalise and undervalue vulnerable people's capacity to obtain benefit from digital health tools.

The scepticism of healthcare provider engagement with digital healthcare provision, specifically SDHRs, is currently creating a gap in the delivery of quality healthcare provision for vulnerable communities. For the healthcare provider, knowledge of and engagement with SDHRs should be regarded and valued as an adjunct to best-practice delivery of all quality healthcare provision.

The persistent ignoring by digital healthcare system developers and researchers of the requirement to fully engage with vulnerable healthcare users and gather personal and context-specific digital healthcare requirements exposes a failure in their understanding of the lived experience of CCCs and their multiple digital healthcare requirements. Failure to engage with and explore the requirements and capacity of vulnerable communities is leading to the development of unsuitable and misinformed digital health tools that are not fit for purpose.

Adopting a CBPR approach to the experience of and engagement with MyHR has produced sustainable benefits related to the personal development of individuals. Since the research, some of the research community continue to maintain their SDHR and continue to encourage their family, community, and healthcare providers to do likewise. The continued engagement with their SDHR provides the perceived benefits of increased awareness of the needs of their CCCs and of remedial actions required to prevent adverse changes in their CCCs. These individuals also perceive themselves as better prepared and informed during clinical consultations.

Informal carer support has transitioned. Having access to the SDHR of a person living with CCCs is perceived as useful in informing their role as carer and advocate. The research community learned new skills and grew in their own community. Some progressed to providing volunteer technology assistance at their rural online and primary care centres and LINC.

#### **6.4.3 Discussion - Reflection**

**Reflection** on the use of a CBPR approach in digital health research identifies its benefits and limitations for vulnerable and wider communities. The research has identified that a CBPR approach can be applied to digital health research to successfully gather context-aware research outcomes.

There is plentiful evidence advocating that researchers and community members actively engage in building trust-centred relationships to successfully implement CBPR approaches (Hills & Mullett 2000; Israel, B et al. 1998; Mannion & Braithwaite 2012; O’Fallon, Tyson & Dearth 2000; Rhodes, Malow & Jolly 2010). This is a critical component of CBPR, and the level and nature of the relationships required for successful CBPR is not typical of those required for other research approaches (Nohr & Aarts 2010; Unertl et al. 2015).

However, while the CBPR literature addresses research capacity development among vulnerable communities (Bergold & Thomas 2012; Minkler 2005; O’Fallon, Tyson & Dearth 2000; Wallerstein & Duran 2006), the topics of technology and digital healthcare capacity-building are absent from the CBPR principles. To fully experience and engage in digital healthcare research requires access to and the ability for capacity development of technology tools. This research emphasises the importance of access to technology and engagement in digital health technology training for vulnerable healthcare users. To allow full commitment by vulnerable healthcare users, it is necessary to acknowledge and include access to technology and digital healthcare capacity-building within the principles of CBPR.

This confirms that there is a need to identify accessible community technology resources and to train communities in technology concepts and digital healthcare tools. Based on a **reflection** of the experience of and engagement with MyHR, it is clear that the identification of technology resources and inclusion of technology and digital healthcare capacity-building can improve access to digital healthcare provision for vulnerable communities. Incorporating technology capacity-building into the principles of CBPR and enabling the community by giving them digital healthcare skills provides personal and contextual opportunities for digital health research.

**Reflection** considers that building technical and digital healthcare capacity affects the way vulnerable healthcare users engage with their healthcare provision. Therefore, it is worth resourcing CBPR so that it can evolve to incorporate the principles of technology and digital healthcare capacity-building. These extended CBPR principles can address the technology and digital healthcare training needs of both vulnerable healthcare users and healthcare providers. On **reflection**, there is an

opportunity to establish other partnerships focused on CBPR within digital healthcare. These partnerships, if appropriately resourced, could assist with identification and dissemination of CBPR best practices within the digital healthcare field and promote the use of consistent, validated measures for the engagement with and effectiveness of SDHRs.

**Reflection** has described the specific benefits of adopting a CBPR approach, and demonstrated an understanding of how CBPR principles enable trust-centred relationships and can evolve to provide digital healthcare outcomes. The research demonstrates how the principles of CBPR can be extended and integrated into digital healthcare research, thereby having real-world impacts on the research community. **Reflection** has also identified challenges associated with the CBPR approach and provided insights into how to address them. Researchers should consider using an extended CBPR approach, particularly for research involving digital healthcare and vulnerable communities.

## 6.5 SUMMARY

Chapter 6 has described the three key research findings, explained how they have answered the research questions, and provided a critical discussion relating the key research findings to the appropriate evidence. The key research finding **tailored facilitation** challenges the paternalistic, inflexible siloed characteristics of models of care frequently found in the current delivery healthcare provision across Australia. **Tailored facilitation** can lead to tangible improvements in the experience of and engagement with MyHR for vulnerable communities, and holds promise as a method to advance population-wide implementation of MyHR. **Tailored facilitation** values the theoretical characteristics of person-centred care from a complex adaptive system perspective.

**Tailored facilitation** reinforced people living with CCCs in rural communities by acknowledging their interconnections. Their cognitive diversity was recognised, and a different way of thinking flourished in the partnerships. There were commonalities and differences in community health, rural, digital technology, and MyHR experiences. All the innovative contrasting perspectives of vulnerable healthcare users in similar situations were considered as motivational ideas.

When vulnerable healthcare users established **tailored facilitation** to support their personal and group experiences of and engagement with MyHR, they demonstrated that they had developed expertise and shared knowledge as agents who were willing to learn. This provided an irreplaceable source of real-world knowledge that was immediately useful to them, their family, their community, and the wider establishment. The research identified the value of including a thorough exploration of vulnerable healthcare users and respecting person-centred requirements, while gathering the concerns of the research community. It drew attention to incompatibilities that, if appropriately acknowledged and addressed, could increase the chance that MyHR can ultimately enhance personal empowerment, integration, and improved quality of healthcare provision.

**Tailored facilitation** motivated community innovation. Co-evolution challenged and considered redefining existing, paternalistic, siloed models of healthcare provision by comparison with the capacity and role of MyHR. Full engagement with MyHR can create continuous, consistent communication and education for healthcare users and providers alike. **Tailored facilitation** allowed time to value and support communication and learning. Contextualising a role for MyHR empowered the vulnerable healthcare users to engage and understand how and why MyHR can provide them with quality digital healthcare provision.

**Tailored facilitation** encouraged self-organisation, data generation and analysis, enabling the partners to compare, collaborate and communicate, explore, expand, and explain their knowledge and expertise without an explicit hierarchical direction in the partnerships. **Tailored facilitation** encouraged storytelling as an effective way to collect explanations, experiences, challenges, and allow creativity in the partners' engagement with MyHR. This ensured a person-centred collaborative digital experience relevant to exploration of the concept of MyHR with real people. The collaboration between the partners and the researcher throughout the research process created new digital health knowledge about personally significant issues that affect the community. This ultimately allowed them to better understand, inform, and bring about change toward quality healthcare provision.

**Resilience** is an adaptive, life-long process, a process of continual learning, a way of coping and adapting to new ways of living with CCCs. Resilience is vulnerable

people taking the initiative to self-organise their symptoms and have control about how illness impacts their lives. The way people manage and their capacity for managing is individual and changes throughout the transitions of CCCs and life.

This key research finding acknowledges the **resilience** of a person living with CCCs in a rural community and MyHR as an enabler of person-centred care from a complex adaptive system perspective. **Resilience** can facilitate the emergence of health in individuals and communities through adaptability, self-organisation, and empowerment.

During this research, a vulnerable community demonstrated and built **resilience** as agents who are willing and able to learn. Once they had experienced and engaged with MyHR they learnt and shared its value as an essential healthcare adjunct with the potential for personal engagement, and as an access point to wider healthcare provision. MyHR provided the opportunity for interaction and organisation, and allowed partners to demonstrate and build on their **resilience** and their healthcare providers' health knowledge in an equitable, cohesive, sustainable manner.

MyHR can provide interconnections that demonstrate and build upon the transitional **resilience** required of the lived experience of CCCs, by offering digital access as an organised approach to healthcare provision. However, when a rural community of people living with CCCs, who are likely to be the most frequent non-health professional users of MyHR, engaged with MyHR, some design issues emerged. MyHR can and should be designed to be accessible and engaging for all, including people with a wide range of physical and cognitive, literacy, and cultural requirements. Lack of skills should not be regarded as a deficiency of the healthcare user, rather as a deficiency in the system. This finding should be regarded as an opportunity and motivation to rectify the system, making quality healthcare provision accessible to all.

Interconnections with MyHR have identified the persisting problem with all SDHRs, a consistent failure to appropriately enquire about and address the essential requirements of all users, such as the rural community of people living with CCCs who were involved in this research. Adoption of MyHR requires an awareness, understanding, and integration of essential resources to allow engagement and equip all stakeholders.

Finally, **resilience** creatively co-evolved to a learning environment for digital transitional healthcare provision. However, healthcare providers were perceived as reluctant to coevolve, preferring to impose a narrow, doctor-defined ‘patient’s agenda’ that was epidemiologically-based and focused on a set of guidelines or protocols (Greenhalgh et al. 2015). Healthcare provision continues to marginalise and undervalue the capacity of healthcare users to obtain benefit from digital health tools. This is identified as a risk that in the long-term may greatly affect the nature and quality of healthcare provision and subsequent health outcomes. Healthcare providers require innovation and support to develop capacity and overcome the factors that inhibit their engagement with SDHRs.

**Reflection** has demonstrated the benefits and challenges of applying a CBPR approach to digital health research. These benefits would not have emerged through a researcher-focused paradigm. The challenges require strong researcher–community partnerships/interconnections that are developed through time, trust, and flexibility on all sides.

**Reflection** on the benefits of applying a CBPR approach to the experience of and engagement with MyHR identified the value in ensuring that research is relevant, and provides options for wider research opportunities, effective recruitment and retention, improved internal validity, the transition of experience into engagement and the development of vulnerable communities.

**Reflection** on the potential challenges of applying a CBPR approach to the experience of and engagement with MyHR identified that time and effort is required to build trust-centred relationships. Other challenges include the requirement for a clear communication style that acknowledges all cultures, a clear vision between the partners and researcher about the research design, identification and recruitment of an appropriate research community, shared research responsibilities, succession planning, and the identification and availability of resources and infrastructure.

**Reflection** has identified that the principles of CBPR can be applied to digital health research to successfully achieve context-aware research outcomes. However, to fully experience and engage in digital healthcare research requires the development of capacity in skills and knowledge related to technology and equipment. This requires



that the principles of CBPR evolve to acknowledge and include digital healthcare technology capacity-building.

**Reflection** considers that future CBPR research can evolve and become an intervention. Building technical and digital healthcare capacity can affect the way vulnerable healthcare users and engage with their healthcare provision.

Chapter 7 concludes this thesis by synthesising the answers to the research questions, comparing these with the appropriate existing evidence, discussing their contribution to research knowledge, acknowledging the scope and limitations of the research, and making recommendations for future work.

# Chapter 7: Conclusion

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Chapter 7 concludes the thesis by seeking to synthesise the discussion provided in Chapter 6, restate the answers to the thesis research questions and how they relate to the appropriate evidence, present the research contributions to digital health knowledge at substantive, methodological, and theoretical levels, state the limitations of the research, and finally, recommend direction and areas for future research.

Chapter 7 is organised into the following sections:

- 7.1 answers the research questions and is divided into subsections that provide answers to Rq1. and Rq2., respectively;
- 7.2 describes and discusses the relationship of the answers to the literature, by extracting key aspects of the relevant literature and explaining how these justify or contradict the research findings;
- 7.3 presents the research contribution and is divided into subsections describing the research contributions to digital health knowledge at substantive, methodological and theoretical levels;
- 7.4 recognises and discusses the scope and limitations of the research;
- 7.5 makes recommendations, discusses the implications of the research at policy and implementation, community, personal, and research levels, and concludes with an autobiographical reflection;
- 7.6 concludes the thesis by synthesising the research that has been previously discussed.

## 7.1 ANSWERING THE RESEARCH QUESTIONS

The rural community identified the research topic, which reflected the concern of their rural community about the capacity in which MyHR may be beneficial for a person living with CCCs in a rural community and what obstacles they may encounter.

The research aim was:

- **Ra1.** To emphasise practical outcomes identified by exploring the experience of people living with complex CCCs in a rural community in their engagement with Australia's shared digital health record, MyHR.

This thesis has answered the following research questions:

- **Rq1.** What is the experience of MyHR for people living with CCCs in a rural community?
- **Rq2.** Why do people living with CCCs in a rural community engage with MyHR?

The exploratory research was guided by a participatory philosophy and paradigm that supported the principles of CBPR. This approach recognised the value of the real-world knowledge that people living with CCCs as a rural research community contributed to extend and co-create new knowledge. Their focus on practical issues and problem-solving provided research and practice evidence that was not only immediately useful and relevant to the community, but also transferable to other communities. Engaging the community throughout the research meant that the usefulness of the outcomes of the research was not left to chance. With the full involvement of community groups, future decisions can be made by policy makers about how to use the information to bring about change.

The experience of and engagement with MyHR needed a unique understanding and acknowledgment of the transitional complex care requirements of vulnerable people living with CCCs in a rural community. The adoption of the theoretical concept of person-centred care from a complex adaptive system perspective assisted in understanding their requirements, and in conceptualising MyHR embedded within a digital transitional complex care pathway. The successful outcome offers MyHR as an opportunity for engagement in a person-centred approach to digital healthcare provision. Using the concept of person-centred care from a complex adaptive system perspective answers the research questions and rationalises the community's experience of and engagement with MyHR.

### 7.1.1 Rq1. What is the experience of MyHR for people living with CCCs in a rural community?

As agents who were willing and capable of learning, people living with CCCs in a rural community wanted to experience and learn more about MyHR and how to digitally integrate and improve their own and others' knowledge about their CCCs. Once involved in the experience of MyHR, they recognised its value as an essential healthcare resource with the potential for person-centred engagement and as an access point to wider healthcare provision. The experience of these vulnerable healthcare users provided an irreplaceable source of information.

**Reflection** on using an extended CBPR approach recognised that the principles endorsed **tailored facilitation** and established interconnections. Partnership understanding of the lived experiences of CCCs and digital health technology changed the patterns of communication and cultivated a collaborative learning environment regarding a topic of interest to the community. This was informed by relevant personal knowledge and community intelligence, which nurtured respect and won trust. The **tailored facilitation** experience of MyHR offered challenges and broadened attitudes regarding digital communication and healthcare provision. The experience of MyHR drew attention to the multiple physical, cognitive, and literacy needs, and a different way of thinking developed in the partnerships. **Tailored facilitation** ensured that commonalities, differences and contrasting perspectives of vulnerable people in similar situations were all considered as innovative and motivational ideas to be resolved.

**Tailored facilitation** allowed the experiences of MyHR to be demonstrated as instinctive **resilience**, the ability to self-organise without external guidance. To contribute and value the experience of MyHR required the use of instinctive **resilience**. The experience of MyHR for people living with CCCs in a rural community identified a pressing need that they be provided with appropriate access to digital technology, contemporary information about CCCs, health and wellbeing, and resources. A **tailored facilitation** experience of MyHR provided an opportunity to build capacity for consistent community and patient-provider communication, learning, and knowledge.

The use of **tailored facilitation** and **resilience** to experience MyHR demonstrates the vulnerable healthcare users' ability to co-evolve and to build learning

environments to allow growth and modify and effect others' development. They were prepared to take responsibility and to develop and display the ability to address the issues of access to quality healthcare provision confronting their community.

At a personal level, **tailored facilitation** supported the opportunity to experience MyHR. Vulnerable healthcare users were provided with the potential to demonstrate and build **resilience**, play a significant role in the research, and take ownership of and responsibility for their health outcomes and health information. They recognised the difficulty in any given healthcare provider being responsible for the aggregation of a person's health record; MyHR provides the opportunity for healthcare users to see new information and ensure that all their healthcare providers have access to their latest reports.

**Tailored facilitation**, experience, iteration, time, and explanation built trust and provided tangible, lasting health benefits for the community. The supportive interdependent learning environment experienced, challenged, and considered redefining existing healthcare provision models. It identified capacity and a role for MyHR in creating continuous, consistent communication and education.

**Tailored facilitation** ensured that a vulnerable community remained open-minded enough to see the national picture, without losing sight of their core values. Their experience of MyHR demonstrated and built **resilience**, which motivated them to resume or assume personal responsibility, to experience, recognise, and question their multiple of CCCs, and to disclose any concerns. Experiencing, discussing, and challenging the concept of MyHR identified two types of valuable information. First, that current models of care, the healthcare system and healthcare providers seriously undervalues the capacity of vulnerable healthcare users to obtain benefit from digital health tools. Second, that for full commitment by vulnerable healthcare users, access to technology and digital healthcare capacity-building must be acknowledged and included in the principles of CBPR. This information is directly useful to the community, to healthcare provision, and for the future research and development of SDHRs.

### 7.1.2 Rq2. Why do people with complex chronic conditions, living in a rural community engage with MyHR?

From the inception of the research, people living with CCCs in a rural community were central to the research and were perceived as agents willing and capable of learning, who were receptive and eager to modify their approach to healthcare provision and the way in which they engaged and communicated their healthcare needs to others. Engagement with MyHR was regarded as an opportunity for interaction and organisation, to build on their own and their healthcare providers' health knowledge in an inclusive and sustainable manner. Engagement with MyHR also identified the value of including a thorough exploration of all the needs of vulnerable healthcare users, respecting personally significant requirements while identifying the contextual concerns of the community.

**Tailored facilitation** valued interconnections and interrelationships, changed patterns of communication and engaged vulnerable individuals in partnerships. Irrespective of personal attitudes toward information and computing, personal **resilience** and partnerships found value and engaged with MyHR as a tool for interconnection and inclusion. MyHR engagement can offer interconnections that improve and empower the transitional requirements of a person living with CCCs by providing digital access as an organised approach to healthcare provision. MyHR can, and should, be designed to be accessible and engaging for all people with varying capabilities. Engagement with MyHR exposed a failure in healthcare provision to appropriately enquire about and address the essential requirements of all users. System developers and healthcare providers must realise that engagement with MyHR requires acceptance, understanding and integration of all essential healthcare provision resources to engage and equip all stakeholders.

Engagement with MyHR demonstrated an instinctive **resilience** and ability to achieve order without external guidance. Engagement and integration of people living with CCCs with the capacity and role of MyHR perceived as a holistic concept identified options for redefining existing paternalistic, siloed models of healthcare provision. Personal and partnership **resilience** and the ability to self-organise enhanced engagement with MyHR. **Resilience** created new knowledge about how personally and contextually significant issues affected and effected their community, to better understand and bring about change.

People living with CCCs in a rural community were ready to co-evolve and engage with MyHR and to demonstrate their ability to learn, grow, modify, and affect each other's development. Their engagement with MyHR challenged existing healthcare provision models and the capacity of MyHR in creating continuous, consistent communication and education. The research showed that to achieve full benefit of the MyHR, existing healthcare provision models need to be redefined to maximise healthcare users engagement with MyHR, where they and their carers, as advocates, are offered the opportunity to communicate their needs, their CCCs, and their main problems in their transitional complex care pathway without overemphasising 'disease' or 'patient' processes. **Tailored facilitation** contextualises a role for MyHR, and allowed vulnerable healthcare users to demonstrate and build **resilience**. In doing so, they become empowered to engage and understand how and why MyHR can provide them with efficient person-centred quality digital healthcare provision.

People living with CCCs in a rural community engaged with MyHR and creatively co-evolved toward a digital transitional CCCs environment. However, the reluctance of healthcare providers to engage with MyHR was presented as a reluctance to co-evolve and a preference for marginalising and undervaluing the capacity of vulnerable communities to obtain benefit from digital health tools, while continuing to deliver paternalistic, siloed models of healthcare provision to vulnerable people living with multiple CCCs in a rural community.

Personally engaging with MyHR, viewing and adding health data, and informing their healthcare providers of their actions, provided partners with the opportunity to define and communicate their personality, their CCCs, and their main problems during their health transitions. By doing so, they assumed and demonstrated a person-centred role within a complex adaptive system.

By extending the principles of CBPR to acknowledge and include access to technology and digital healthcare capacity-building, new knowledge has been created. Personally significant real-world insights that reflect and affect a rural community have been provided. Involving and integrating vulnerable people living with CCCs with the capacity and role of digital health technology identifies options for redefining existing healthcare provision models. MyHR should be embedded in digital complex care pathways, and serve to better inform all stakeholders including

developers, healthcare service providers, healthcare managers, government bodies, and healthcare pressure groups, but most importantly, healthcare users.

By building capacity in personally trusted, supportive, and appropriate environments, digital health technology can emphasise doing rather than being. The provision of access to capacity-building in digital health technology provides opportunities to be personally responsible, engaged, and integrated into healthcare provision. However, the design and implementation of a digital person-centred approach requires a thorough exploration of the inexperience and emotional responses of all users. The contribution of the role of the informal carer as an advocate is essential for all vulnerable healthcare users. This should be acknowledged and identified in MyHR. The future design and implementation of MyHR should respect and value accessibility and engagement for all stakeholders with multiple abilities, including but not limited to physical, emotional, neurological, psychological, and cognitive abilities.

By reflecting on person-centred care from a complex adaptive system perspective the research has identified the value of guiding an inclusive, practical process of self-organisation and a thorough exploration of the capacity of all users living with CCCs as agents who learn. Interconnections acknowledge, respect, and value all person-centred aspects and focus the concerns of the community, prevent incompatibilities and increase the chance that SDHRs co-evolve to enhance personally significant evidence and to improve quality of care. The lessons learned from the research should inform the community, healthcare provision, and policy, ultimately leading to innovation and essential changes in the user experience of and engagement with SDHRs for future quality healthcare provision.

## **7.2 RELATIONSHIP WITH LITERATURE**

SDHRs are now globally acknowledged as essential for the delivery of quality healthcare provision. Governments and policy makers are recognising that adoption of SDHRs will improve integration, thereby delivering improved quality and efficiency and encouraging all individuals to access and aggregate their health data electronically (eHealth Initiative 2012; Greenhalgh et al. 2009; Nohr et al. 2016; Project Integrate 2016; Whetton 2005).



This research draws attention to the perspectives of vulnerable healthcare users. The people who could benefit most from SDHRs are those who create the largest burden on healthcare delivery; i.e., people living with CCCs in rural communities, who are disadvantaged because of their limited access to efficient, quality healthcare provision (eHealth Initiative 2012; Murray, E et al. 2005). SDHRs can offer a contemporary continuum of quality healthcare provision for disease prevention, management, and treatment, and reduce disparities in care. However, although Australia launched MyHR in 2012, it remains without any personally or contextually significant implementation framework or resources (Almond, Cummings & Turner 2013, 2016, 2017).

This research draws attention to disparities in access to current healthcare provision. This limits the engagement of vulnerable healthcare users, including people living with CCCs in rural communities. In turn, this condones the continued delivery of healthcare provision that marginalises and undervalues the capacity of vulnerable healthcare users to obtain benefit from digital health tools.

The research findings demonstrate the importance of active listening to vulnerable healthcare user experiences in building capacity into future healthcare provision that is responsive to the diversity of personally significant and community experiences. Healthcare provision continues to be delivered within a narrow, doctor-defined 'patient's agenda' at a designated time and venue organised to suit the healthcare provider (Greenhalgh et al. 2015). It should be encouraged to accept and support the concept of the informed healthcare user and their desire to engage, rather than considering them as 'threatening intruders trespassing into a forbidden zone' (Eysenbach & Jadad 2001, p. 6).

Acceptance, inclusion, and access to technology and digital health education are critical to the engagement and involvement of vulnerable communities. Accepting and encouraging the routine participation of healthcare users (measurement, monitoring, and reporting of their CCCs symptoms and medications) and encouraging them to remain active partners in their healthcare provision and members of their community, can significantly assist healthcare users and providers to understand and transition through their multiple diseases. Valuing the expertise of people living with CCCs in a rural community motivated them to challenge the need

for interactive and cooperative relationships with their healthcare providers. Engagement with MyHR provided opportunity for healthcare users to see new information and ensure that all their healthcare providers had access to their latest reports, and to understand that experiences are key in the delivery of digital, person-centred quality healthcare provision.

Defining a role for MyHR, organising and characterising its essential elements, and viewing MyHR as person-centred care from complex adaptive system perspective challenges the current paternalistic, siloed models of healthcare delivery and provides inclusion, opportunity, and context. These elements can empower and inform all stakeholders of the practical possibilities inherent in the delivery of quality digital healthcare provision. Further, accessible and timely information about healthcare provider services could deliver continuous feedback to help improve the outcomes for vulnerable healthcare users, and to ensure that the correct skill mix meets their transitional needs at any given time.

There is a requirement for vulnerable communities to be engaged and valued during their supplementation of their transition through their CCCs by MyHR. Engaging and integrating people living with CCCs in a rural community with their digital health care provision required a considered approach to their complex transitional healthcare requirements, and a better understanding of their experience of and engagement with their SDHR.

People living with CCCs are not units or factors of production; they live in families, communities, and broader communities. The literature has long suggested that evidence-based practice must be based on knowledge co-created by the community (Israel, B et al. 1998; O’Fallon, Tyson & Dearry 2000). More recently, van Gemert-Pijnen et al. (2011), Sturmberg (2014) and Greenhalgh et al. (2015) suggested that improving the uptake and influence of digital health technologies requires evaluation methods that go beyond the use of experimental designs and randomised controlled trials, because these are not predisposed to evaluate the impact of digital health interventions in transitional complex situations. These authors advocated the implementation of rigorous qualitative studies.

However, this research suggested that most published health and digital health research has minimal contextual or healthcare user input; the evidence relates to

decisions and outcome measures that a vulnerable healthcare user would not themselves have identified. Evidence-based practice is therefore biased toward clinical or information system frameworks. In principle, most current research omits real-world choices that can lead to more suitable and successful outcomes for all users.

To address research capacity development among vulnerable communities, a critical component of CBPR is that researchers and community members build trust-centred relationships (Hills & Mullett 2000; Israel, B et al. 1998; Mannion & Braithwaite 2012; O’Fallon, Tyson & Dearry 2000; Rhodes, Malow & Jolly 2010).

However, the role of technology and digital healthcare capacity-building is absent from the principles of CBPR. This research emphasises the importance of access to technology for the engagement in digital health technology and capability building for vulnerable healthcare users. For full commitment of vulnerable healthcare users, access to technology and digital healthcare capacity-building must be acknowledged and included in the principles of CBPR.

This research sought to capture real opinions on what matters most to a particular person and community at a particular point in their CCCs journey(s), and to identify how and why a SDHR can assist. The research acknowledges a requirement to address the scarcity of healthcare resources for dealing with the increasing burden of CCCs, especially in vulnerable populations. It suggests that technology and digital health advances, specifically MyHR, make it possible to implement applications intended for direct use by all healthcare users and providers, to expand access to resources. Further, the research commends that MyHR be implemented as person-centred from a complex adaptive system perspective to prevent further practical incompatibilities, and to extend and complement the current research on shared decision-making.

### **7.3 RESEARCH CONTRIBUTION**

This research makes significant contributions to health informatics and digital health knowledge at substantive, methodological, and theoretical levels. These are described below.

### 7.3.1 Substantive level

The research contributes at a substantive level in three ways by identifying:

- the requirements for successful delivery of qualitative digital health research in a rural community environment;
- a rural community's use of and requirements for a SDHR;
- improving understanding of the experience of and engagement with a SDHR of a person living with CCCs in a rural community.

A rural community of people living with CCCs participated in the conduct of a transparent, flexible, iterative research, which explored their experiences of and engagement with MyHR. All decisions were shared between the partners and were representative of the interests of the community (people living with CCCs in a rural Tasmanian community) and the researcher (the academic institution). By doing this, the community has provided a valuable source of substantive information. They demonstrated their capabilities for identifying, implementing and accomplishing digital health research. This improved their understanding of and their involvement in the health of their community. It also improved research understanding, which in turn can inform future community, national, and international practice and research.

The digital health research described in this thesis provides substantive insight into how to involve and engage as a research community the unpredictable world of a particular group of people (people living with CCCs), in a particular context (a rural Tasmanian community), and in a flexible, transferable process. This kind of research can be conducted across different communities or regional settings to guide all stakeholders toward providing insight for future implementation of SDHRs. **Tailored facilitation** supported the community's experience of and engagement with MyHR in their own context, supporting their development of solutions for future implementation.

The embedding of MyHR in digital transitional complex care pathways offers healthcare users improved involvement in the requirements of their CCCs. However, substantive factors must be taken into account to increase the likelihood of a successful experience of and engagement with MyHR. These include early involvement of the community and individuals, and experience and understanding of

their physical, psychological, neurological, and cognitive requirements of MyHR, with consideration of the competencies of all users.

The research contributes significantly at a substantive level. It provides research knowledge about tailored approaches that can be adopted to improve the experience of and engagement with SDHRs for people living with CCCs in rural communities. The research informs future work, regionally, nationally, and internationally.

### 7.3.2 Methodological level

The research contributed at a methodological level by successfully introducing and engaging a rural community in participatory digital health research. Guided by the principles of CBPR and using a transparent, systematic, thematic framework approach to data analysis to allow understanding the experiences of and engagement of the research partners with MyHR, this research has contributed in three ways:

- The approach adds value by actively challenging, engaging, and empowering people living with CCCs as partners throughout the research process, leading to the identification of new real-world knowledge. Past evidence-based practice has depended on gathering conflated, objective, quantitative data, upon which decisions about what constitutes effective or efficient practice have been based.
- It provided a balanced valuation of the contribution of a traditionally difficult-to-engage community with academic digital health research in the development of new knowledge about community practice. This approach greatly enriched the quality of the research. **Tailored facilitation** acknowledged and incorporated approaches that addressed genuine community concern, to extend and complement the current focus on shared decision-making while ensuring the validity and reliability of the findings
- For people to fully experience and engage in digital healthcare research requires their access to and capacity development in technology tools. This research contributes by identifying that technology and digital healthcare capacity-building is absent from the principles of CBPR. Therefore, the principles of CBPR need to evolve to acknowledge and include the need for capacity-building in technology and digital healthcare.

The principles of CBPR guided the research community in a relevant, planned, systematic, problem focused, sustainable approach to societal change. Further, using a thematic framework approach to data analysis promoted continued community inclusion in a comprehensive, transparent, and flexible approach to their complex research process. Using CBPR methodology and a thematic framework approach to data analysis allowed for community involvement and the development of in-depth understanding regarding the experience of and engagement with MyHR, from the perspectives a rural community of people living with CCCs. This validated the emergence of themes within and between each contact and within and between each theme.

Using CBPR principles, the data were collected via group meetings, semi-structured interviews, and the researcher's reflective journal. As a methodology, CBPR required the direct involvement of and organised learning between the users and the researcher; this was achieved. This research has contributed to and advanced digital health research by implementing a methodology that investigates the understandings and meanings within a particular community as they experience them in their unpredictable world, as they become adopters of digital health tools. It raises a concern regarding the pressing requirements for rural community access to capacity building in technology expertise and digital healthcare provision.

The thematic framework approach to data analysis identified a need to view the experience of and engagement with MyHR as a transitional CCCs care pathway from the perspective of a particular person in a particular community with unpredictable CCCs. The key findings from this research emerged after the iterative data analysis approach identified themes and the instances were compared within and between data and themes, allowing a better understanding and interpretation of the data. By drawing on the thematic framework approach to enrich data analysis and interpretation, the research provides insights that can be applied to assist future implementation of MyHR.

The principles of CBPR methodology and the structure of a thematic framework for data analysis provided a rigorous, validated guide to, and conceptual understanding of, the process required for the experience of and engagement with MyHR by vulnerable healthcare users. To extend and complement the current focus on shared

decision-making, researchers should become comfortable with evolving the principles of CBPR to include capacity-building in technology expertise and digital healthcare provision, to engage and obtain personally significant evidence in a real-world context while exploring the digital healthcare provision dynamics of all communities.

The research contributes significantly at a methodological level. The adoption of an evolving CBPR research methodology and thematic framework approach to data analysis is transferable and can inform future digital health provision at community, regional, and national levels.

### **7.3.3 Theoretical level**

At a theoretical level, the research contributes to new digital health research knowledge conducted as participatory person-centred care from a complex adaptive system perspective. The research emphasises the need for MyHR to be viewed as a shared digital health system operating within a broader context of continuing and preventative healthcare provision. As a result, the research proposes that the person, community, healthcare provider, and educational institutions should view SDHRs as a fundamental resource to be included in any model of quality healthcare provision. Digital health researchers should acknowledge and incorporate person-centred care from a complex adaptive system perspective, challenge and balance their focus on shared decision-making, collect and apply contextually significant evidence on how to deliver quality healthcare provision. Research designs should include participatory codesign rather than purely controlled experiments.

This contribution challenges the continued paternalistic, siloed, episodic implementation process of digital healthcare provision. This research has identified that healthcare provision is perceived as marginalising and undervaluing the capacity of vulnerable healthcare users to obtain benefit from digital health tools.

This research has not identified any current practical assistance for or models of the experience of or engagement with MyHR in rural communities of people living with CCCs. However, despite increasing costs, low voluntary registration, little evidence of use, and no evidence of engagement, Australia continues to roll out MyHR. The research suggests that further consideration and investigation through the lens of person-centred care from complex adaptive system perspective is needed to

understand what is required to allow the experience of and engagement with MyHR for people living with CCCs in rural communities (Almond, Cummings & Turner 2013, 2015, 2016, 2017).

The research also provides evidence that questions the current implementation process for MyHR and provides a contextual understanding of the experience of and engagement in MyHR that can contribute to future local, regional, and national implementation research in Australia. MyHR, when viewed as a dynamic digital health system supporting a person's transitional digital CCCs care pathway, can evolve over time. In context, MyHR continues to be influenced by international and national initiatives. At the local level, individuals, families, communities, and current healthcare provision can influence this understanding. International and local insights combined can provide greater understanding of the requirements for MyHR. From a personal or community perspective, it is important to understand the role of MyHR as a digital health system embedded within a transitional CCCs care pathway.

In mid-2018, MyHR opt-out registration rolls out nationally, and a critical mass will emerge. As a strategy, embedding MyHR within a transitional complex model of care offers the opportunity for person-centred care to be viewed from a complex adaptive systems perspective and to influence the experience of and engagement with MyHR. Consideration and acknowledgement will be required from a user perspective: all stakeholders will have different understandings of and requirements for MyHR, the value of which will vary within and between instances. However, it is crucial to incorporate person-centred approaches to extend and complement the current focus on shared decision-making, and to prevent further digital incompatibilities.

Having understood MyHR from substantive, methodological, and theoretical perspectives, this research has clarified the characteristics necessary for successful experience of engagement with MyHR from the perspective of people living with CCCs in a rural community.

## **7.4 SCOPE AND LIMITATIONS**

As a researcher, it is important to recognise that all research methods have strengths and weaknesses, and to show how the chosen research process has addressed these



limitations. The sparse populations of rural communities make smaller sample sizes a reality of research in these areas (Moore & McCarron 2015). However, because of the nature and anticipated depth required from the data collection, and the large amount of time invested with the rural community, it was not considered practical or necessary to recruit a large number of partners. The unpredictable nature of living with CCCs may have been a limitation. This was taken into consideration early in the research design; because the research process was not dependent on the inclusion of large numbers of partners, the loss of a small number from the research would not have rendered it invalid. Future studies that require the generation of real-world evidence could be methodically captured and balanced with statistically significant evidence collected from separate populations (Greenhalgh et al. 2015).

The researcher recognises that a selection bias may have been introduced by the use of Rural Primary Health Services, Tasmania to identify potential partners. However, the research design identified a purposeful sampling technique as most suitable to identify potential partners and obtain rich examples of personally and contextually significant experience, thereby gaining meaningful information while making the most effective use of limited resources (Barbour 2001; Patton 1990; Tongco 2007).

Every effort was made to apply rigour throughout the research process and to test and confirm the findings with the groups and partners. All transcripts were included and studied; this was considered necessary to complete a process that ensured that all data from all groups and partners were considered and that data not commonly repeated were not overlooked (Cottrell & McKenzie 2010). Using respondent validation (member checking) throughout the research ensured the qualitative data analysis was verified and rigorous. Explaining the findings, as written for a wider audience who require an overview different from the explanation of a partner or group, to the research community required careful explanation of the potential for apparent discrepancies. At each encounter, the research community's role was one of validation, to reduce error and also produce more data, which in turn required interpretation (Mays & Pope 2000).

Although findings from qualitative research are not always regarded as transferable, this in-depth research provides useful data for all stakeholders working with vulnerable communities. The researcher believes that the findings may be

transferable to other vulnerable communities, including indigenous populations, professional groups in rural communities, a younger cohort, those with severe mental health disease, or those with severe disability, all of whom warrant future work.

A further possible criticism or bias may be that because of the partners' close relationship with the researcher, the partners may have been more likely to report positive rather than negative experiences. This was considered early in the research design by the researcher recognising their reflexive role throughout the research, as discussed and described in section 3.5 and Table 18. The research also draws attention to the principles of CBPR: the researcher's commitment to ensuring that the topic investigated came from within the community, acknowledging that the researcher acted as a facilitator who was well-trusted and embedded in local knowledge and opinions (Chenoweth & Kilstoff 1998; Hansen 2006b). Section 3.6 has described how the research community ensured that the principles of CBPR were addressed.

Using a thematic analytical framework provided a transparent approach to the data analysis. It offered transparent results and conclusions that can be related back to the original data. Data analysis was undertaken concurrently with and continued after data collection. This allowed for flexibility and retrieval of data to show others how decisions were reached. As an approach to data analysis, the framework approach provided a clear track of how data moved from group or interview to transcripts and to themes. It also allowed the community to work together and consider their progress while providing a clear audit trail, thereby improving dependability (Ritchie & Lewis 2003; Swallow et al. 2014; Ward et al. 2013).

## **7.5 RECOMMENDATIONS**

This section provides recommendations for policy and community and personal implementation, for future research, and an autobiographical reflection by the researcher. Research needs to consider what people say they do, what they are doing, how they translate their beliefs into actions and how they consider their options.

### **7.5.1 Policy and implementation recommendations**

In Australia, there is a relatively small body of work that specifically relates to the vulnerable healthcare user's experience of and engagement with MyHR. The

findings of this research recommend that at organisational and policy levels, focus and value should be placed on the following areas.

There must be a willingness of politicians to contest the role of health professionals, to place more trust in decisions made by healthcare users and communities, and to combat media criticism when things go wrong. Politicians need to support healthcare users in co-constructing their own identity rather than accepting one constructed by 'experts'. Second, the practical feasibility of greater co-production cannot be gauged from a small research study. Further research will identify the practical scope for co-production in other contexts.

Even when vulnerable people are informed, empowered, and physically and cognitively able (and especially when they are not), they rarely inhabit the world of research. They live in the context of the transitional world of a particular person in a particular family or community. The community identification of a real-world opportunity to gain experience of and engagement with MyHR has provided a valuable source of here-and-now healthcare user experience.

Contemporary evidence-based healthcare emphasises the importance of listening to and acting upon the experiences of all stakeholders to help shape future strategies. These must include and be responsive to the diversity of personal capabilities and experiences. Valuing the resilience and expertise of people living with CCCs empowers them to consider interactive and cooperative relationships with their healthcare providers. At policy and implementation levels, there needs to be recognition and understanding of all personal and community experiences and perspectives, which are considered key in the delivery of digital quality healthcare provision.

The outcomes of this research indicate that people living with CCCs in a rural community have the capacity to determine, engage, collaborate, and communicate their healthcare needs, and in doing so, derive opportunity for equity, empowerment, and satisfaction. Using a participatory person-centred approach engaged directly with traditionally invisible or hard-to-involve, but directly affected, people and communities. The approach captured knowledge, ability, and opinions, while facilitating a process of understanding and empowerment that has been largely marginalised in digital health research, to the detriment of results and solutions.

For an efficient, equitable model of engagement, involvement, and integration to work, there needs to be a better understanding of the regional and local infrastructure and systems and training required to engage all stakeholders in the utility of MyHR. A coordinated community approach is required to redefine existing healthcare provision models. In respect to the specific findings of the research, there are a number of projects that could be undertaken to enhance the uptake and sustainability of MyHR and better understand its limitations.

The WHO and its regional office in the Americas (Pan American Health Organization) have recently (June 2017) released the ‘Handbook for Electronic Health Records Implementation,’ for public consultation. This research could support policy and decision makers at regional and organisational levels (including those without technical knowledge) in their provision of relevant feedback to improve the document by addressing the most relevant challenges of implementing SDHRs.

### **7.5.2 Community and personal recommendations**

The essential function of any SDHR is to deliver improvements in healthcare provision, experience and ultimately, outcomes. Consequently, any digital health application should be continuously evaluated to ensure accountability and ongoing improvement.

This research has evaluated the experience of and engagement with MyHR. It recommends that the community not only looks at how MyHR can help, but also spends time and effort to overhaul the practicalities of the implementation process to achieve the ultimate goal, quality healthcare provision. When implementing the relatively new shared digital health solution, MyHR, it is import to separate healthcare provision, which needs to be maintained and enhanced, from the processes that need to be changed and improved. Healthcare user and healthcare provider communication needs to look beyond the ‘what we do’, to include some questions and explanations as to ‘why do we do the things we do?’ and ‘how could we do things better?’

A coordinated community participatory approach is required to redefine and contemporise existing healthcare provision models. Expanding this research to other communities, including indigenous populations, professional groups in rural

communities, a younger cohort, those with severe mental health disease or severe disability, is required to understand the benefits and challenges of MyHR.

Follow up research to re-evaluate personal and community engagement with MyHR after tailored facilitation has been removed will allow for assessment of whether:

- MyHR has continued to be used for personal healthcare notes and summary and whether healthcare professionals have engaged. This would provide further data on the personal advantages of MyHR.
- the community online, primary care, and LINC centres have continued their provision of technology resources and volunteer availability in the form of a ‘buddy system’ to support capacity-building. This would evaluate the opportunity for future roll out of the experience and engagement with digital health information and MyHR.
- **Tailored facilitation** should be considered as a future community model for the successful implementation of MyHR.

### 7.5.3 Future research recommendations

Future research needs to accurately reflect and acknowledge that communities can identify research problems, and be involved in research design, choice of outcome measures, and interpretation and dissemination of findings.

Researchers should become comfortable with the use of participatory paradigms and extending the principles of CBPR for studying and exploring people living with CCCs in their real-world context, and the dynamics of SDHRs as person-centred care from a complex adaptive systems perspective.

Researchers should become comfortable with the use of extended CBPR principles to engage multiple communities, which may help recruit more diverse and representative samples to digital health research.

Researchers should become comfortable with personally and contextually relevant evidence that is collected systematically in the here-and-now, evaluated for rigour, and valued as complementary to statistically significant evidence. This would allow different approaches to digital health research to provide complementary insights.

Future research into SDHRs should consider what people say they do, what they are doing, how they translate those beliefs into actions, and how they consider their options to extend and complement their current focus on shared decision-making.

#### **7.5.4 Autobiographical reflection**

Research evidence of the implementation of SDHRs is currently reported as statistical evidence or drawn from the perceived user need, resulting in a design focused on meeting the requirements of healthcare providers or healthcare systems that overlooks the needs of the healthcare user. The current implementation of SDHRs is a paradox.

The paradox is that policy makers, health informaticians, system designers, researchers, and healthcare providers are discussing, building, reviewing, and implementing a SDHR based on how it can integrate and intervene in a healthcare user's health management. However, in the meantime, as with this research, healthcare users are building collaborative communities aimed at supporting and informing each other. Consequently, there are at least two bodies of knowledge emerging; that which is immediately explicit and useful in a professional context, and community-shared knowledge that is actually being used by people managing their complex conditions. Both are developing separately, or in silos, rather than being *shared* or in dialogue with one another. The author recommends commissioning CBPR research to challenge and explore the *shared* experiences of engagement with MyHR for *all* stakeholders. Future research must ensure that MyHR is researched as a *Shared Digital Health Record*, a real opportunity to meet the real person-centred requirements of MyHR from a complex adaptive system perspective.

CBPR offered the opportunity to spend time in the real world, and provided respite from the constraints of healthcare provision and the indifference and conflation of the academic environment. The research challenged me to call on my deepest aspirations for healthcare provision and higher education practice: to live a meaningful life by being of service and working to reduce inequality. There is an important role for CBPR in reducing disparity. The growing interest in and evolution of CBPR challenges us to remain conscious about our practices. We need to maintain opportunities for self-reflection about our institutions, our cultures, and ourselves.

During the research, as a ‘guest’ in the community, I was always listening for the time when the partnerships intensified. During data collection in one group, I was asked why I was doing research, ‘what are you getting by working with us, it’s an odd thing to do because we’re so out of the way?’ This straightforward question shocked me, and although initially it made me feel uneasy, it also opened up a deeper honesty and led to all of us sharing perspectives. I reflected during the research that the most important values are integrity coupled with humility.

## 7.6 CONCLUSION

This thesis commenced by expressing two concerns. First, the challenges experienced by people living with CCCs in rural communities in obtaining equitable access to quality healthcare provision. Second, the low rate of adoption and the challenges in practical implementation of Australia’s shared digital health record, MyHR. These concerns raised two research questions, which were addressed using a qualitative CBPR methodology, a three-phase approach to data collection, and a three-phase thematic framework approach to data analysis. Data was collected at partner and group levels, and examined and compared as a community sample. Data analysis revealed linkages between personal and contextual requirements, and abilities to demonstrate and build understanding, capability, and access to digital healthcare provision. These were discussed as **tailored facilitation, resilience, and reflection**, factors essential to consider when reviewing the experience of and engagement with MyHR.

This research makes significant contributions to health informatics and digital health knowledge at substantive, methodological, and theoretical levels. At a substantive level the research has provided real-world evidence of the requirements of and how and why people living with CCCs in a rural community experienced and engaged with their SDHR. The results demonstrate the successful delivery of participatory digital health research in a rural community, the value given by the research community to the use of and requirements for MyHR, and an improved understanding of the requirements for a person living with CCCs to experience and engage with MyHR.

At a methodological level, the research adds value by actively challenging, engaging, and empowering people living with CCCs. As partners throughout the research

process, they identified new, personally significant real-world knowledge. This encouraged vulnerable healthcare users, who are traditionally difficult to engage, and community commitment and involvement in a process of identifying the value of digital healthcare provision. However, the principles of CBPR need to evolve to incorporate technology and digital health capacity-building.

At a theoretical level, the research has contributed new digital health research knowledge about healthcare provision conducted as person-centred care from complex adaptive system perspective. The research emphasises the need for healthcare provision to value healthcare users' capacity to obtain benefit from digital health tools. SDHRs need to be viewed as a shared digital health system operating within a broader context of continuing and preventative healthcare provision. As a result, the research proposes that the person, community, healthcare provider, and educational institutions should view SDHRs as an essential adjunct to quality healthcare provision, viewed as person centred care from a complex adaptive system perspective, and accepted as a contemporary model of quality digital healthcare provision.



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# Appendices

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## APPENDIX A - LIST OF PUBLISHED RESEARCH PAPERS

Journal Article
Almond, H and Cummings, EA and Turner, P, "An Approach for Enhancing Adoption, Use and Utility of Shared Digital Health Records in Rural Australian Communities", <i>Studies in health technology and informatics</i> , <b>235</b> pp. 378-382. ISSN 0926-9630 (2017) [Refereed Article] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]
Nohr, C* and Parv, L* and Kink, P* and Cummings, E and Almond, H and Norgaard, JR* and Turner, P, "Nationwide citizen access to their health data: analysing and comparing experiences in Denmark, Estonia and Australia", <i>Bmc Health Services Research</i> , <b>17</b> Article 534. ISSN 1472-6963 (2017) [Refereed Article] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]
Almond, H and Cummings, E and Turner, P, "Avoiding Failure for Australia's Digital Health Record: The Findings from a Rural E-Health Participatory Research Project", <i>Studies in Health Technology and Informatics</i> , <b>227</b> pp. 8-13. ISSN 0926-9630 (2016) [Refereed Article] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]
Bamgboje-Ayodele, A and Ye, M and Almond, H and Sakulwichitsintu, S, "Inside the Minds of Doctoral Students: Investigating Challenges in Theory and Practice", <i>International Journal of Doctoral Studies</i> , <b>11</b> pp. 243-267. ISSN 1556-8881 (2016) [Refereed Article] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]
Nohr, C* and Wong, MC and Turner, P and Parv, L* and Gilstad, H* and Koch, S* and Hardardottir, GA* and Hypponen, H* and Almond, H and Marcilly, R* and Sheik, A* and Day, K*, Nohr, "Citizens' access to their digital health data in eleven countries – a comparative study", <i>Studies in Health Technology and Informatics</i> , <b>228</b> (1) pp. 685-689. ISSN 0926-9630 (2016) [Refereed Article] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]
Almond, H and Cummings, E and Turner, P, "Using community based participatory research as a method for investigating electronic health records", <i>Studies in Health Technology and Informatics</i> , <b>208</b> pp. 40-44. ISSN 0926-9630 (2015) [Refereed Article] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]
Wong, M-C and Almond, H and Cummings, E and Roehrer, E and Showell, C and Turner, P, "Patient Centred Systems: Techno-Anthropological reflections on the challenges of 'meaningfully engaging' patients within health informatics research", <i>Studies in Health Technology and Informatics</i> , <b>215</b> pp. 52-66. ISSN 0926-9630 (2015) [Refereed Article] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]
Almond, H and Cummings, E and Turner, P, "Australia's personally controlled electronic health record and primary healthcare: Generating a framework for implementation and evaluation", <i>Studies in Health Technology and Informatics</i> , <b>188</b> pp. 1-6. ISSN 1879-8365 (2013) [Refereed Article] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]
Conference Publication
Nohr, C* and Wong, MC and Turner, P and Almond, H and Parv, L* and Gilstad, H* and Koch, S* and Hardardottir, GA* and Hypponen, H* and Marcilly, R* and Sheik, Z* and Day, K* and Kushniruk, A*, "Citizens' access to their digital health data in eleven countries – a comparative study", <i>Proceedings of MIE2016 at HEC2016 - Exploring Complexity in Health: An Interdisciplinary Systems Approach</i> , 28 August - 02 September 2016, Munich, Germany, pp. 685-689. ISBN 978-1-61499-677-4 (2016) [Refereed Conference Paper] [ <a href="#">Full Text</a> ] [ <a href="#">Detail</a> ] [ <a href="#">Upload RODA</a> ]

## **APPENDIX B - CHECKLIST FOR ADHERENCE TO THE PRINCIPLES OF CBPR**

**Checklist for Adherence to the Principles of Community Based Participatory Research (Hills & Mullett 2000).**

### **Systematic and Planned Process**

- How does your research plan systematically address the research question?
- What is the logical relationship between the research question, methodology and methods?
- How does the research process incorporate the multiple ways of knowing?

### **Relevant to the Community**

- Who generated the research issue?
- How is this a community issue?

### **Requires Community Involvement**

- What mechanisms are in place to include people in the planning, management and dissemination of the research?
- Are all the stakeholders who need to be involved, involved?
- How will decisions be made about the research process?

### **Problem Solving Focus**

- What is the community's practical problem or issue that is being addressed?
- How will researching this issue help the community?

### **Focuses on Societal Change**

- What changes are anticipated?
- How is the research process structured to allow for reflection and iteration?
- Who will implement the changes?
- How is theory generated from and for practice?

### **Sustainability**

- What will the community have at the end of the research?
- How does the research outcome enhance human flourishing?

### **Reference**

Hills, M & Mullett, J 2000, 'Community-Based Research: Creating Evidence-Based Practice for Health and Social Change paper presented to Qualitative Evidence-based Practice Conference, , May 15-17 2000, Coventry University.

## APPENDIX CI - Full ethical approval (H0013781)

Social Science Ethics Officer  
Private Bag 01 Hobart  
Tasmania 7001 Australia  
Tel: (03) 6226 2763  
Fax: (03) 6226 7148  
Katherine.Shaw@utas.edu.au



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HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

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26 February 2014

Assoc Prof Paul Turner  
Computing and Information Systems  
Private Bag 87

Student Researcher: Helen Almond

*Sent via email*

Dear Assoc Prof Turner

Re: FULL ETHICS APPLICATION APPROVAL  
Ethics Ref: **H0013781 - An investigation into the use and impact of the personally controlled electronic health record (PCEHR) in people with complex chronic conditions**

---

We are pleased to advise that the Tasmania Social Sciences Human Research Ethics Committee approved the above project on 26 February 2014.

This approval constitutes ethical clearance by the Tasmania Social Sciences Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approval of other bodies or authorities is required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.

A PARTNERSHIP PROGRAM IN CONJUNCTION WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au).
3. Incidents or adverse effects: Investigators should notify the Ethics Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
4. Amendments to Project: Modifications to the project must not proceed until approval is obtained from the Ethics Committee. Please submit an Amendment Form (available on our website) to notify the Ethics Committee of the proposed modifications.
5. Annual Report: Continued approval for this project is dependent on the submission of a Progress Report by the anniversary date of your approval. You will be sent a courtesy reminder closer to this date. **Failure to submit a Progress Report will mean that ethics approval for this project will lapse.**
6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely

Katherine Shaw  
Executive Officer  
Tasmania Social Sciences HREC

A PARTNERSHIP PROGRAM IN CONJUNCTION WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

## **APPENDIX CII - Interim ethical approval (H0013781)**

Dear Assoc. Prof Turner

Ethics Ref No: H0013781

Project title: An investigation into the use and impact of the personally controlled electronic health record (PCEHR) in people with complex chronic conditions

This email is to confirm that your Ethics Progress Report was approved by the Tasmania Social Sciences Human Research Ethics Committee on 16/3/2015.

Your next Ethics report is due on 26/2/2016. A reminder email will be sent prior to the next due date.

If your project is completed before the date shown above, a final report form must be forwarded to me as soon as possible.

It is not standard policy to send a formal confirmation of the report approval. Please let us know if your circumstances require a formal letter of report approval.

Should you have any queries please do not hesitate to contact me.

Kind regards

Lynda Hobman

--

Lynda Hobman

Ethics Administrative Officer

Office of Research Services

University of Tasmania

Private Bag 01

Hobart TAS 7001

Phone: (03) 6226 6254

Fax: (03) 6226 2765

Email: [Lynda.Hobman@utas.edu.au](mailto:Lynda.Hobman@utas.edu.au)

Web: <http://www.research.utas.edu.au/>



## APPENDIX CIII - Final ethical approval (H0013781)

To: Paul Turner;

Cc: Liz Cummings; Helen Almond;

● You forwarded this message on 2/21/2016 12:08 PM.

Dear Assoc Prof Turner

Ethics Ref No: H0013781

Project title: An investigation into the use and impact of the personally controlled electronic health record (PCEHR) in people with complex chronic conditions

This email is to confirm that your Ethics Final Report was approved by the Tasmania Social Sciences Human Research Ethics Committee on 15/2/2016.

Should you have any queries please do not hesitate to contact me.

Kind regards

Katherine

**Katherine Shaw**

Executive Officer, Social Sciences HREC

Office of Research Services | Research Division

University of Tasmania

Private Bag 1

Hobart TAS 7001

T +61 3 6226 2763

[[www.utas.edu.au/research](http://www.utas.edu.au/research)][www.utas.edu.au/research](http://www.utas.edu.au/research)



CRICOS 00586B

## APPENDIX D - RURAL PRIMARY HEALTH SERVICES TASMANIA AGREEMENT

### TASMANIAN HEALTH ORGANISATION SOUTH

#### RURAL PRIMARY HEALTH SERVICE

Ash Cottage  
Lyell Highway Ouse  
TAS 7140



Contact: Tracey Turale  
Phone: (03) 6287 2001 / 0429 433 664  
E-mail: tracey.turale@dhhs.tas.gov.au

Helen Almond  
PhD Candidate  
School of Computing and Information  
University of Tasmania  
Hobart, Tasmania 7001  
Australia

Dear  
Helen

The Rural Primary Health Services of the Central Highlands and Southern Midlands confirm their participation in your PhD Community Research Project commencing in February 2014.

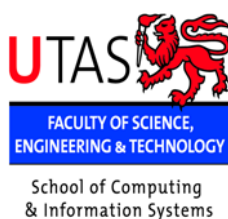
The Health Promotion workers in these regions, Chris Worthington, Corina McCarthy and Kristina Szymanski with support from me will work with you in recruiting appropriate candidates for a focused Health Promotion and Lifestyle Modification Program. All staff will assist in delivering health promotion activities and opportunities for research candidates to focus on their health goals. All staff will also participate in each of the planned focus groups in their region.

Yours sincerely

Tracey Turale

Manager / Rural Health Service Coordinator  
Rural Primary Health Service  
Central Highlands / Southern Midlands / Bruny Island

## APPENDIX E - PARTNER INFORMATION SHEET



### *Partner Information Sheet*

The experience of and engagement with Australia's shared digital health record, the Personally Controlled Electronic Health Record - for people with complex chronic conditions living in a rural community

**This information sheet is for partners of the above named research.**

**The research will be conducted in Tasmania during 2014 - 2016. It will contribute to understanding the use and impact of the PCEHR for people with complex chronic conditions.**

#### 1. Invitation

You are invited to take part in research being conducted in partial fulfilment of PhD studies being undertaken by Helen Almond under supervision of Associate Professor Paul Turner, located in the School of Computing and Information Systems, and Dr. Elizabeth Cummings in the School of Nursing & Midwifery, University of Tasmania, Hobart, Australia.

#### 2. What is the purpose of this study?

To investigate the experience of and engagement with the PCEHR for people with complex chronic conditions and

- to identify and understand how the use of the personally controlled electronic health record can impact on self-management in and self-efficacy for people with complex chronic conditions
- to develop the personal expertise of people with complex chronic conditions in the use of the personally controlled electronic health record
- using the experiences of people with complex chronic conditions conceptualise a framework to contribute to the implementation and evaluation of the personally controlled electronic health record.

#### 3. Why have I been invited to participate?

As a person with more than one complex chronic condition, living in rural Tasmania, recruited to a Rural Health Promotion and Lifestyle Modification Program, you have been invited to participate in this research investigation to provide data required by the community and researcher in an endeavour

- to understand people with complex chronic conditions personal requirements of the personally controlled electronic health record, in a rural community
- to identify meaningful use of a personally controlled electronic record and facilitate learning opportunities for people with complex chronic conditions
- to explore the use and impact of the personally controlled electronic health record on communication.

#### 4. What will I be asked to do?

In the current context of your knowledge of the Personally Controlled Electronic Health Record you will be asked to attend group meeting and one to one meetings and answer straight forward questions regarding use, usability and utility concerning:

1. The experience of the Personally Controlled Electronic Health Record
2. The engagement with the Personally Controlled Electronic Health Record

#### 5. The conduct of the focus group discussion & semi-structured interviews

- There will be a maximum of 10 partners in each group discussion, semi-structured interviews will be face to face, one to one, the partner and the researcher
- Each group discussion will be held local to the partners and last for approximately 1-2 hours (including tea breaks)
- Each semi-structured interview will be held at a mutually convenient time and location and last for approximately 45 - 60 minutes
- All partners in the project will be people, over 18 years, with more than one complex chronic condition, recruited to a rural health promotion and lifestyle modification program
- Participation is voluntary and partners may discontinue the project at any stage without effect
- The group discussions will be recorded using an audio-voice recorder. The data will be transcribed and used as; a focus for review and feedback at subsequent meetings; and data for analysis and interpretation by the researcher
- The semi-structured interviews will be recorded using a digital voice recorder. The data will be transcribed and used for analysis and interpretation by the researcher
- Names or any other identifiers will not be recorded or transcribed as part of the data collection. Any personal identifiers will be represented by codes to

protect partners' privacy and anonymity. Only codes will be published in any publications generated as a result of analysis of interview data

- All research data, field notes, transcripts and digital recordings, will be securely stored within a secure data repository at the University of Tasmania, Australia for five years from the publication of the study results, and that after this period all data will be destroyed as per University of Tasmania, Australia policy
- Access to the electronic data is password protected, with access granted only to Helen Almond, Associate. Professor. Paul Turner and Dr. Elizabeth Cummings

#### 6. Are there any possible benefits from participation in this study?

As this is a community based research project it is expected the community and individuals can benefit from:

- The facilitation of personal and community participation in learning new skills, gaining knowledge and insight whilst contributing to the meaningful use of the PCEHR, a new communication technique
- The facilitation of personal and community participation in learning new skills, gaining knowledge and insight into the health benefits of self-management and self-efficacy.
- The facilitation of personal and community participation in learning new skills, gaining knowledge and insight whilst contributing the research process

#### 7. Are there any possible risks from participation in this study?

There are no anticipated risks arising from participation in this study. Every effort will be considered and maintained to allay apprehension, expected in this type of investigation. Where apprehension, is identified it will be appropriately managed by those suitably qualified health professionals involved with research project and referral to other appropriate health professionals known to individual partners will be made.

The registration and training component of the research project, stage 3, will cover the importance ensuring personal and health information is kept secure. The eHealth record system has been designed to make sure this happens.

There are strict rules in the Personally Controlled Electronic Health Records Act 2012 and the Privacy Act 1988 that govern how information will be managed and protected for those people who choose to register for an eHealth record.

The Australian Government strongly encourages consumers to take steps to stay safe online. Partners will keep their login and password for the eHealth record system

secret and secure. The Australian Government's website [www.staysmartonline.gov.au](http://www.staysmartonline.gov.au) offers a lot of useful advice and tips to consumer about IT security in the home.

8. What will happen to the information when this study is over?

All transcripts and digital recordings will be kept securely at University of Tasmania, Australia data repository for 5 years.

9. How will the results of the study be published?

A copy of the research thesis and any subsequent publications in peer-reviewed journals arising from this research will be available to the Community. No individually identifiable data will be included.

10. What if I have questions about this study?

If you have any questions about this study please contact:

Helen Almond, School of Computing and Information Systems, University of Tasmania, Private Bag 100, Hobart, Tasmania 7001 Australia. Telephone: (61) 3 6226 7530 Email: [Helen.Almond@utas.edu.au](mailto:Helen.Almond@utas.edu.au)

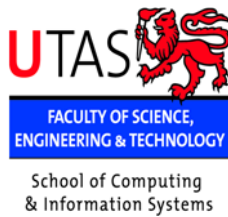
Or

Associate Professor Paul Turner, School of Computing and Information Systems, University of Tasmania, Private Bag 100, Hobart, Tasmania 7001 Australia, Telephone: (61) 3 6226 6240, Email: [Paul.Turner@utas.edu.au](mailto:Paul.Turner@utas.edu.au)

The Tasmanian Social Sciences Human Research Ethics Committee has approved this study. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research partners. Please quote ethics reference number: **H0013781**.

**Please keep this information sheet for your reference. If you are willing to involve in this research, please sign the attached consent form.**

## APPENDIX F - CONSENT FORM



The experience of and engagement with Australia's shared digital health record, the Personally Controlled Electronic Health Record - for people with complex chronic conditions living in a rural community

**The consent form is intended for all people who wish to become involved in the above named research as partners.**

1. I agree to take part in the above named research study
2. I have read or have had read and understood the Information Sheet for this study
3. The aims and objectives of the study have been explained to me
4. I understand that the study involves collecting data on: the use and impact of the personally controlled electronic health record (PCEHR) for people with complex chronic conditions
5. I understand that all research data will be securely stored within a secure data repository at the University of Tasmania, Australia for five years from the publication of the study results, and that after this period all data will be destroyed as per the University of Tasmania, Australia policy
6. I understand that I can seek clarification on any questions asked by the researcher as part of the interview process
7. I understand that the researcher will maintain confidentiality and that any information I supply to the researcher will be used only for the purposes of the research
8. I understand that any publication based on this research will not contain my name or any other personal identifying data and that my identity will be represented by a code which will not allow anyone to trace data to my identity
9. I understand that my participation is voluntary and that I may withdraw at any time without effect
10. *For interview partners only:* If I so wish, I may request that any data I have supplied be withdrawn from the research up until December 2014

*For focus group discussion:* I am aware that data I have supplied cannot be withdrawn from the research.

Partner's name:

---

Partner's signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Statement by Researcher**

☐

I have explained the project and the implications of participation to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

If the Researcher has not had an opportunity to talk to partners prior to them participating, the following must be ticked.

☐

The partner has received the Information Sheet where my details have been provided so partners have had the opportunity to contact me prior to consenting to participate in this project.

Researcher name:

---

Researcher signature:

---

Date: \_\_\_\_\_

The Tasmanian Social Sciences Human Research Ethics Committee has approved this study. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number: H0013781.



## APPENDIX G - GROUP GUIDE AND MEMO

### Memo

Date	Time
Venue	Duration
Group	_____

*Diagram of seating plan (with partner codes)*

*Where did the group take place?*

*Was it suitable?*

*Does anything need to be changed for future groups?*

*How many people took part?*

*Who else took part?*

*Did they work well as a group?*

*Were there any adverse group dynamics?*

*What can I learn from this group next time?*

*Did the group work well?*

*Does it need to be altered or improved?*

*What were the main themes, which arose from this group?*

*Does anything need to alter for the next group?*

*Any further information required?*

*By whom?*

*By when?*

## Group guide

To develop a framework for conceptualising people with complex chronic conditions experience of the personally controlled electronic health record that can be used to contribute to implementation and evaluation.

- **Group**
- Introductory welcome to group
- Presentation, the researcher/facilitator will re-introduce the research project. The presentation will revisit the project aims, project timeline, data collection methods, confidentiality of data collected, ability to withdraw from the study at any time and the inclusion of identified 'Person Responsible'.
- The presentation will encourage primarily questions from the group.

In the event no questions are forthcoming

- Proposed Q1. Do you have any questions about the project aims?
- Proposed Q2. How do you think you may use the PCEHR?
- Proposed Q3. How do you think this project can benefit the community?
- Proposed Q4. Do you have any comments about how the focus groups and or the individual interviews can be best used in this community project?
- Proposed Q5. Do you have any question regarding the PCEHR registration and training?
- Proposed Q6. Do you have any other questions regarding the project?

Audio recordings, of all the groups, will be transcribed in full, reflexive group memos will be marked on the transcription. These will serve as a record and data for the researcher and at subsequent group meetings allow for partner review of previous results, confirm accuracy, encourage feedback and act as a meeting outline.

## **APPENDIX H - SEMI-STRUCTURED INTERVIEW GUIDE**

Audio-recorded semi-structured interviews will be between the individual partner and researcher.

### **Pre -intervention Semi-structured Interview Guide**

The transcribed interview data will provide the researcher with; a clear demographic profile; the partners personal journey including, family history, personal history, computer awareness and use; and ascertain the issues confronting the individual partner regarding implementation of the PCEHR.

Q1. Demographic data; sex, age, ethnicity, place of birth, level of education, occupation, marital status, person responsible

Q2. Have you been involved in any projects before?

Q3. Partner personal journey

- Tell me about your family?
- Tell me about yourself?
  - Who is involved in your healthcare?

Q4. Computer awareness and use

- What do you think about computers?
- Tell me what do you use a computer for?
- Before you joined this project what did you know about of electronic health records?
- Before you joined this project had what did you know about the PCEHR?

Q5. Are there any aspects of the project that you are unsure about?

### **Post – PCEHR intervention audio-recorded semi-structured interview guide**

Individual partners and the researcher will ascertain their views of the use, usability and utility of the PCEHR.

Partners will be invited to share their PCEHR personal health notes with the researcher.

Q1 Use, usability and utility of the PCEHR.

- Tell me about your experiences with the PCEHR registration and training process?
- Tell me have you used your PCEHR?
- Tell me how have you used your PCEHR?
- Do you think the PCEHR has helped you and in what way?
- Have you used your PCEHR in any other way?
- Do you share your PCEHR with other people and how?

Q2 Would you like to share what you have recorded in your PCEHR with me?

Q3 What do you think you and the community have gained from this PCEHR research project?

## APPENDIX I - DATA ANALYSIS - INITIAL ANALYTICAL FRAMEWORK

### *Phase One*

#### **1. Demographic data**

*Q1.1 Gender*

*Q1.2 D.O.B*

*Q1.3 Ethnicity*

*Q1.4 Place of Birth*

*Q1.5 Education*

*Q1.6 Employment/Occupation/Career History*

*Q1.7 Marital Status*

*Q1.8 Carer Status*

#### **Q2. Past or other research involvement (Ro.1)**

#### **3. To understand and identify the complexities of the person, their family, their background and their health (Ro1)**

#### **Q3 Partners personal journey**

*Q3.1 Tell me about your family*

*Q3.2 Tell me about yourself*

*Q3.2.1 and your health*

*Q3.3 Who is involved with your healthcare*

*\*Health Practitioners*

*\*Health goals*

#### **4. To identify & understand partners, likes/dislikes, use/non-use and Impact of computers (Ro1.2)**

#### **Q4.1 Computer awareness & use**

*Q4.1.1 What do you think about computers?*

*Q4.1.2 What do you or would you use a computer for?*

#### **Q4. 2 To identify & understand any prior knowledge with regard to EHR or PCEHR (MyHR)**

*Q4.2.1 What did you know about the electronic health record before you joined the project*

*Q4.2.2 what do you know about the PCEHR (MyHR) before you joined the project*

#### **5. To re-affirm partner's wish to continue in the project**

*Q5. Were or are there any aspects of the project that you are unsure about?*

### *Phase Two*

#### **6. Personally Controlled Electronic Health Record (MyHR) registration experience & early engagement (Ro2)**

### *Phase three*

#### **7. To identify & understand partner's experience of and engagement with the PCEHR (MyHR) (Ro3)**

##### **Q7. Personally Controlled Electronic Health Record (MyHR) - Post Intervention Experience and engagement**

*Q7.1 Tell me about your experiences since the PCEHR registration*

*Q7.2 Have you used your PCEHR?*

*Q7.3 Tell me how have you used your PCEHR?*

*Q7.4 Do you think the PCEHR has helped you and in what way?*

*Q7.5 Has the PCEHR helped you with your lifestyle management program and in what way?*

*Q7.6 Have you used your PCEHR in any other way?*

*Q7.7 Have you shared/told your PCEHR with other people and how?*

*Q7.8 Future use for PCEHR?*

#### **8. To understand participants value of A community and CBPR (methodology)**

##### **Q8 What do you think you and the community may have gained from this (PCEHR/MyHR) research project?**

*\*Q8.1 Why do you live in a rural Community?*

*\*Q8.2 What do you think is there a value to performing research in rural communities?*

*\*Q8.3 What do you think the lifestyle differences are urban v rural?*

*Q8.4 would you like to provide a photograph of what 'living rurally' means to you?*

#### **9. Other comments**

*Note \*emerging issues identified by researcher or participants*

## APPENDIX J - MULTIPLE CCCS IDENTIFIED BY PARTNERS

Body System	Complex Chronic Condition				
<b>Cardiovascular</b>	Hypertension	Heart disease	Cerebro-vascular accident		
<b>Ear, nose and throat</b>	Impaired hearing	Profoundly deaf			
<b>Endocrine</b>	Diabetes	Thyroid			
<b>Gastrointestinal</b>	Irritable bowel disease	Diverticular disease			
<b>Haematological</b>	Blood disorder	Haemo chromatosis			
<b>Immunology</b>	Multiple allergies	Auto immune disease			
<b>Infection</b>	Cellulitis	Chronic ear infection			
<b>Locomotor</b>	Osteoarthritis	Psoriatic arthritis	Gout	Degenerative lumbar spine	
<b>Lymphatic</b>	Primary lymphodema				
<b>Neurology</b>	Tinnitus	Vertigo	Multiple sclerosis	Parkinson disease	Chronic pain
<b>Psychiatric</b>	Depression	Anxiety	Stress		
<b>Respiratory</b>	Asthma	Sleep apnoea	Sinusitis	Emphysema	Lung cancer
<b>Reproductive</b>	Breast cancer				
<b>Urology</b>	Prostate cancer				
<b>Vision</b>	Macular degeneration	Glaucoma	Retinopathy		